**Questionnaire on the right of persons with disabilities to the highest attainable**

**standard of health ( Special Rapporteur on the rights of persons with disabilities.)**

1***. Please provide information on existing or planned legislation and policies to***

***ensure the realization of the right to health of persons with disabilities, including***

***current challenges and good practices***.

Recently in 2016, the Indian Parliament passed and bought into force ‘The Rights of Persons with Disabilities Act, 2016’ (henceforth referred to as RPD Act) broadly based on the rights recognized and enumerated under the CRPD, in order to fulfil its obligation thereunder. Although above-mentioned law contains an elaborate article on healthcare (Section 25) covering a range of concerns including barrier-free access, free healthcare for certain category of PwDs, as per economic basis to be specified, in close vicinity, prevention of disabilities, sexual and reproductive health, training of health professionals and awareness generation there is no specific mention of non-discrimination in health services/delivery and health insurance covers. Moreover, the RPD Act in its present form under section 3(3) on non-discrimination actually grants the power to discrimination against a PwD if the act or omission is a proportionate means to achieve a legitimate aim, without creating any checks and balances for the use of such power.

However, the actual realization of these rights and promised services under section 25 of the RPD Act need to be further enumerated upon through the provisions of rules. Unfortunately, the central level Rules notified in mid-2017 do nothing in the way of addressing the issue of healthcare. Therefore, it is now left to the individual prerogative of each State to define the rules on the section on health in the law. It can be seen from the example of some of the State Rules (in drafts as well as finalized) that the section on healthcare has not been covered. For example there is no mention of health under the floated rules for Delhi and the final rules for the State of Madhya Pradesh (<http://www.socialjustice.mp.gov.in/Portal/Public/View_Acts.aspx?id=42> – last accessed on 27th March 2018). Furthermore, many parts of the provision under Section 25 would be realized through schemes and programmes but there is not stated timeline for the making of such schemes and programmes by the concerned government.

In light of the fact that the state of governmental healthcare set ups remains poor and in many areas non-existent alongside a fast growing privatized health industry especially in urban settings, there is a dire need to specify through rules how section 25 on healthcare in the RPD Act would be progressively realized, with certain specifications for the 21 categories of disabilities covered under the law.

In addition a new law on mental health titled “The Mental Healthcare Act, 2017’ (hereinafter referred to as the MHA) has also been passed. Again modelled on the basis of the CRPD, it looks at provision of affordable and quality mental healthcare services within easy geographic reach as per section 18 of MHA. Mental health services would also impact persons affected by leprosy, as being diagnosed can lead to an overwhelming sense of stigma, self-stigma and depression. However, it remains to be seen how this law will be implemented in the years to come.

With particular reference to leprosy, the treatment drug combination known as MTD is supplied to the Government of India for free and thus is available to all persons diagnosed and under treatment for leprosy who are registered under the leprosy database of the National Leprosy Eradication Programme of the Government of India. Additionally, under rehabilitation financial incentive is provided to persons affected by deformities due to leprosy for reconstructive surgery. This financial incentive is to continue under the RPD as well. This helps to reduce the deformity and increase the functionality of the affected limb of the individual and also reduce the stigma attached to the visual image of the deformed limb.

Apart from these existing legislations on disability, there are two proposed bills specifically on the issue of leprosy. As there are over 119 civil and criminal laws in India that discriminate against a person affected by leprosy on the grounds of the disease, the Law Commission of India, a quasi-judicial body of the Government of India had proposed the adoption of a specific legislation on leprosy titled ‘Eliminating Discrimination Against Persons Affected by Leprosy and Their Family Members Bill, 2015’ (Hereinafter referred to as EDPAL Bill) in its report 256. The purpose of the said bill was to address the issue of the discriminatory provisions while also providing for the rights and entitlements of persons affected by leprosy and their family members. The proposed bill takes a broad aspect of healthcare including not only the aspects of leprosy treatment but access to general healthcare including mental health services of counselling. It also encompasses the right to be treated humanely and training and awareness generation. Report no. 256 which also includes the EDPAL Bill was submitted to the Ministry of Law and Justice in April 2015. Since then, the same was forwarded to three Ministries in the same year (Health and Family Welfare, Ministry of Law’s concerned department and the Road Transport and Highways) for their comments. Responses from all three Central Ministries remains pending as of now, according to the concerned website. (<http://legalaffairs.gov.in/sites/default/files/status%20of%20law%20commission%20report_0.pd> – last accessed on 28th March 2018)

In the meanwhile, a member of the Rajya Sabha (House of Lords), a renowned lawyer, Mr. KTS Tulsi has filed a Private Member’s bill on leprosy model around the central idea of EDPAL. It is titled ‘The Rights of Persons Affected by Leprosy and Members of Their Family (Protection Against Discrimination and Guarantee of Social Welfare) Bill, 2017’ and has been introduced into the Rajya Sabha in the winter session of Parliament in 2017. It has now been sent to the roaster for its listing for discussion. The said Bill is centers around non-discrimination and clearly covers the aspect of non-discrimination in the provision of health services. On the lines similar to EDPAL, the Bill covers the aspect of healthcare from treatment of leprosy and its consequences like reactions to reconstructive surgeries to general access to healthcare to barrier-free access to awareness and training of healthcare providers.

**RECOMMENDATIONS**

1. We urge that a recommendation be made to amend the central government rules under the RPD Act, 2016 to include detailed provisions on Section 25 of the Act detailing with healthcare.
2. We urge that a recommendation be made the appropriate government make the schemes and programmes under Section 25 of the RPD Act in a time bound manner not exceeding more that three years form the date of the notification of the Act in collaboration with representatives of all the 21 enlisted disabilities.
3. We urge that a recommendation be made to pass a specific law on leprosy as suggested by the Law Commission of India by either adopting the private member’s bill already in Parliament or substantiating EDPAL and putting it through the law-making process.

2. ***Please provide any information and statistical data (including surveys, censuses,***

***administrative data, literature, reports, and studies) related to the exercise of the***

***right to health of persons with disabilities in general, as well as with particular***

***focus in the following areas:***

• Availability of barrier-free general healthcare services and programmes,

which take into account all accessibility aspects for persons with disabilities;

• access to free or affordable general healthcare services and programmes,

including mental health services, services related to HIV/AIDS and universal

health coverage;

• access to free or affordable disability-specific healthcare services and

programmes; and

• access to free or affordable health-related habilitation and rehabilitation

goods and services, including early identification and intervention.

3***. Please provide information on discrimination against persons with disabilities in***

***the provision of healthcare, health insurance and/or life insurance by public or***

***private service providers.***

Report No. 256 of the Law Commission of India, identifies ‘The Life Insurance Act, 1956’ as containing a provision which allows the charging of higher premiums on the ground of leprosy.

4. ***Please provide information on the observance of the right to free and informed***

***consent of persons with disabilities regarding healthcare, including sexual and***

***reproductive health and mental health services.***

5. ***Please describe to what extent and how are persons with disabilities and their***

***representative organizations involved in the design, planning, implementation***

***and evaluation of health policies, programmes and service.***

The Leprosy Mission Trust India (TLMTI) amongst other leprosy related non-governmental organisations have been working in close partnership with the government’s health department, the National Leprosy Eradlication Programme (NLEP) on addressing the health-related issues of leprosy. TLMTI in 2017 worked on the Sparsh campaign by the NLEP division from its implementation to roll out stage, to sensitise the villages about leprosy and the need for early detection of the disease and non-discrimination of the affected people through the platform of the gram-panchayats.

Data on Sparsh

 

