

Conference of the state parties to the CRPD-2018

Mainstreaming leprosy in the disability rights discourse

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While it is estimated that there are about 4 million people with leprosy related disabilities, the actual figure could be much higher if the definition of a person with disability according to Convention on the Rights of Persons with Disabilities (CRPD) is applied in the case of persons affected by leprosy and if data is collected on the basis of the Washington Group short set of Questions. The psycho-social disabilities amongst persons affected by leprosy is often not measured and this could perhaps bring significant number of persons affected by leprosy within the definition of persons with disabilities.

Article 40 of the CRPD enunciates that the states that have ratified the CRPD shall come together in the conference of the state parties (CoSP) to discuss issues of relevance in implementing the convention effectively. The 2018 CoSP witnessed participation from 177 countries that have ratified the convention which included 21 leprosy endemic countries apart from senior officials of the national governments, relevant UN agencies, National Human Rights Institutions (NHRIs) NGOs, DPOs and individuals involved in promoting and protecting the rights of persons with disabilities. The Leprosy Mission (TLM) participated in this conference in its organizational capacity and also as the member of the ILEP.



The 2018 CoSP was perhaps the first meeting of the state parties in which the rights of person's with leprosy related disabilities was discussed. TLM was one of the select organization to make a statement in the civil society forum on the Article 33(3) of the CRPD dealing with engagement of the national governments in monitoring the implementation of the convention. TLMs presence as an organization

representing persons affected by leprosy was in many ways an eye-opener for the Civil Society Forum about issues related to leprosy.

TLM was also one of the six NGOs to make a statement in the Round Table on political participation and equal recognition before the law. This platform was thoroughly used to resonate messages on how persons with leprosy related disabilities are the only minority group within the disability population to be 'legally discriminated' and unequally recognized before the law. The Round Table indeed turned out to be a podium for sensitizing and raising awareness of the disability stakeholders about the barriers faced by persons affected by leprosy in their daily life. It also became a platform for TLM on behalf of ILEP to draw the attention of the government representatives such as Ministers and Secretaries of the 177 countries including 21 leprosy burden countries, members of the National Human Rights Commission of different countries and NGOs towards Principles and Guidelines to eliminate discrimination against persons with leprosy related disabilities and to make an appeal for inclusion of information on the steps taken to implement the guidelines within the national reports of the state parties to be submitted to the CRPD Committee.

The side event organized by the TLM along with the Nippon Foundation and Disabled People's International (DPI) underscored the importance of mainstreaming the rights of persons with leprosy related disabilities within the DPI agenda and in combating stigma and discrimination at the community level with the involvement of persons with leprosy related disabilities as members of the Disabled People's Organizations (DPOs).

Messages on upholding dignity and rights of persons with leprosy related disabilities and their hither to exclusion from the disability rights discourse echoed in key side events organized during the CoSP. The side event of the Commonwealth Secretariat and DFID regarding the Global Disability Summit took note of the need to include the issue regarding stigma and discrimination against persons with leprosy related disabilities within the relevant thematic of the global disability summit. TLM received an assurance from the Secretary, Government of India, Department of Disabilities to expedite the process of ending 119 discriminatory laws against persons affected by leprosy in India. A message on behalf of TLM Global Fellowship and ILEP was communicated to World Bank that their 'Disability Inclusion and Accountability Framework' should ensure that persons with leprosy related disabilities are not left behind in the process of achieving the 2030 agenda.

The CoSP 2018 ushered a new phase within the disability movement to address the rights of persons with leprosy related disabilities under the CRPD framework and in ensuring accountability of the state parties to the CRPD to end stigma and discrimination against persons affected by leprosy. It was indeed a wakeup call for the disability stakeholders to go beyond rhetoric's and to make sincere efforts to address the rights of minority groups within disability population such as those affected by leprosy to make sure that no one is left behind in achieving the SDGs.