

Concept Note

Side-event on *“Inclusion of Invisible and Neglected Disabilities (Leprosy) in Climate-change Action and Disaster Risk Reduction for a Sustainable and Resilient Future”* at the 15th Session of the Conference of States Parties to the CRPD

1. Background

The current COVID-19 pandemic has highlighted several inequalities and exposed many fragilities, shortcomings and risks faced by marginalized and vulnerable groups. Persons with disabilities, the world’s largest minority group, account for 15% of the world’s population and their number is increasing due to crisis and disaster situations, aging populations and medical advancements. They have been affected the most during the current pandemic, facing several barriers to inclusion.

It has also been reported that such disaster and emergency situations often disproportionately impact the disability community. This is particularly true for invisible and neglected disabilities that account for almost 80% of all disabilities which are either underrepresented or unrecognized in many disability policies and platforms. In particular, the situation is exacerbated for neglected disabilities such as those associated with leprosy, which is one of the most stigmatized and discriminated diseases in the world. 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 where leprosy is endemic, trapping them in a vicious struggle with poverty, unemployment, lack of basic amenities, insanitary conditions, overcrowding and malnutrition, among other social ills.

Persons with disabilities are more vulnerable not only because of their experiences of adverse socio-economic outcomes such as high poverty rates and lack of essential services but, they are more likely to be left behind and abandoned placing them at a heightened risk in such situations. Social protection is considered an important policy response to address the poverty, vulnerability and the social inclusion of marginalized and vulnerable communities in the context of livelihoods and income, access to healthcare and education, among others. However, in order to ‘build back better, sustainable and resilient’, States need to promote inclusive social protection policies, programmes and initiatives that are designed and implemented through participatory approaches informed by the lived experiences and on-the-ground realities of all persons with disabilities and their intersectionalities, with particular focus on invisible and neglected disabilities such as leprosy.

The Sendai Framework for Disaster Risk Reduction 2015-2030 and the 2030 Agenda for Sustainable Development, guided by the principle of ‘Leave No One Behind’ and in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), encourages States Parties towards the meaningful participation of all persons with disabilities and to engage them as advocates for disaster risk reduction and climate adaptation as they best understand their own needs and vulnerabilities. According to the Sendai Framework Monitor, in 2021, about 118 countries reported developing their national and local disaster risk reduction strategies as mandated under the Framework. However, a study conducted by UN Women reports that only 26 countries have a disaster risk reduction policy for at-risk groups such as women, children and youth, persons with disabilities, poor people, migrants, indigenous peoples and older people.

Unfortunately, even with an estimated 3 to 4 million people living with visible impairments or disabilities due to leprosy, the leprosy community continues to be invisible among the disability sector often lacking recognition and access to the various rights and provisions related to UNCRPD in many countries, including lacking equal participation in policy-level discussions within the disaster risk management and climate-adaptation discourses. This means that the needs and vulnerabilities of the

leprosy community are not addressed or taken into consideration while developing the national and local policies and programmes.

But, with climate change leading to more frequent and severe natural disasters including increasing incidents of war and crisis situations, excluding leadership of persons with disabilities including persons affected by leprosy and their representative organizations, in prevention preparedness, response and recovery plans including climate-related policy and decision making, will only lead to exacerbating the disabilities and inequities within our society. Thus, following the slogan of “Nothing about us, without us”, it is critical that inclusion and accessibility of a diversity of disabilities are at the heart of all development policies and programmes. The involvement of all persons with disabilities throughout the planning, implementation and recovery phases is important to lower the risk and raise resilience in the face of natural and human-induced hazards.

Thus, the side event at the Conference of States Parties will aim to: 1) identify policy gaps and implementation challenges, 2) confront barriers that prevent participation of the disability community, particularly persons affected by leprosy, 3) identify opportunities for optimizing a disability inclusive disaster risk reduction through the lived experiences of persons with disabilities, including persons affected by leprosy, and 4) identify examples of good practices of inclusion within the disaster risk management and climate-related decision-making at local, national, regional and global levels.

While highlighting the need for participatory approaches for inclusion of persons with disabilities in the development process particularly in climate action, disaster risk reduction and resilience against natural disasters in the context of COVID-19 and beyond, the side event will also start a dialogue on the need to build awareness on the needs and inclusion of invisible and neglected disabilities such as leprosy to ensure that States Parties recognize a diversity of disabilities and provide them with equal access and opportunities as other mainstream disabilities under the national laws in compliance with the UNCRPD. The keynote address by the Special Rapporteur, in preparation of the report to be submitted to the 77th session of the UN General Assembly, will seek to facilitate such a dialogue and recommend strategies for creating enabling systems and processes for neglected disabilities to be able to access disability rights and provisions using the UNCRPD mechanism and to fulfil the commitment to disability inclusion and to ‘leave no one behind’!

2. Details

- I. Date: June 16, 2022
- II. Time: 8:30 am to 9:45 am (EST – New York)
- III. Topic: “Inclusion of Invisible and Neglected Disabilities (Leprosy) in Climate-change Action and Disaster Risk Reduction for a Sustainable and Resilient Future”
- IV. Related Theme / Sub-theme: “Building disability-inclusive and participatory societies in the COVID context and beyond (or Participation of persons with disabilities in climate action, disaster risk reduction and resilience against natural disasters)”
- V. Format: Online (Zoom)
- VI. Language: English
- VII. Accessibility: International sign and Captioning
- VIII. Programme

0:05	Welcome Remarks <ul style="list-style-type: none"> - Mr. Arman Ali, National Centre for Promotion of Employment for Persons with Disabilities (DPI India)
0:08	Keynote Address <ul style="list-style-type: none"> - Dr. Floyd Morris, Member, UNCRPD Committee
0:09	Special Message <ul style="list-style-type: none"> - Ms. Alice Cruz, UN Special Rapporteur on elimination of discrimination against

	persons affected by leprosy and their family members
0:08	Testimony from person affected by Hansen's disease: - Mr. Dinesh Basnet, President, IDEA Nepal
0:35	Panel Discussion (7 mins for each speaker) <ul style="list-style-type: none"> ● Perspective from the disability and leprosy sector: <ul style="list-style-type: none"> - Dr. Sruti Mohapatra, Founder and CEO, Swabhiman, India - Ms. Lilibeth Evarestus, Hope Initiative, Nigeria - Ms. Ipul Powaseu, Papua New Guinea ● Perspective from supporting organizations: <ul style="list-style-type: none"> - Dr. Takahiro Nanri, Sasakawa Health Foundation, Japan (policy level) - Mr. Nazmul Bari, Director, Centre for Disability in Development (CDD), Bangladesh (programme level)
0:05	Q&A
0:05	Closing Remarks - H.E. Mr. KIMURA Tetsuya, Ambassador, Permanent Mission of Japan to the United Nations

Moderator: Mr. Arman Ali, National Centre for Promotion of Employment for Persons with Disabilities (DPI India)

Organizers: Disabled Peoples' International and Sasakawa Health Foundation

Co-sponsors: Permanent Mission of Japan to the United Nations, Centre for Disability in Development (CDD) and National Centre for Promotion of Employment for Persons with Disabilities (NCPEDP)