

Statement by the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz

Opening plenary of the Neglected Tropical Disease NGO Network – NNN – 2020’s Conference “Accelerating to 2030: Building Resilient NTD Programmes in a Changing World”

Paula Brandão has called upon us not to look at neglected diseases but to neglected groups of people. People affected by leprosy and other NTDs experience the same conditions of deprivation, structural disadvantage, stigmatization, poor access to State services and diminished participation, which I refer to as subordination, in trying to avoid the risks of concepts such as vulnerability and resilience that invisibilize power relations. I prefer to speak of subordination and systemic change.

Subordination hinders achieving the NTDs and SDGs framework. At the macro level – subordination is expressed in the disproportionate impact on NTDs of the growing tendency to turn health into a commodity; at the intermediary level of the State – subordination is expressed in the lack of priority given to NTDs that, together with the limited resources of middle and low income countries, leads to gaps in health systems and coverage that severely impact groups of people that already strive with barriers to access (such as lack of income to take public transportation or dependency of women on third party authorization – usually on men’s authorization - to get medical care); at the micro level - subordination is expressed in the limited structural competence of the health-care workforce (meaning capacity in cultural, linguistic, gender and socioeconomic characteristics of users), among other issues related to discrimination and limited participation of users in health services.

Looking at your question from the viewpoint of subordination means taking into consideration power relations and moving, as Paula Brandão says, from a disease-centered model to a people-centered model, as well as to the actual enforcement of human rights for all. From a

human rights perspective, all rights are interrelated. The right to health is inseparable from the right to an adequate standard of living, which is closely connected to substantive equality. Substantive equality means that equality under the law may not be sufficient to ensure that marginalized groups can enjoy the same rights as everybody else. Covid-19 illustrates not only how subordinated groups experience a disproportionate impact of the current crisis, although they may be equal to others under domestic law, but also how a human rights approach to emergency relief must recognize existing capacity within affected populations, ensure their participation in humanitarian aid and promote their development and autonomy. It must not just provide relief to passive beneficiaries. So, how do we proceed towards substantive equality and systemic change? The answer to such question is of course too complex for our limited time, but what I have said regarding the Covid-19 crisis gives us some clues.

Systemic change can only be achieved through enabling affected groups to have a voice and choice. Their autonomy, active citizenship and democratic engagement in public affairs are key for any sustainable action. Without this, law in books (and by analogy written public health strategies and signed SDGs) will in great measure not be converted into law in action, that is to say, into reality in people's lives. Effective, and not just tokenistic participation of the target groups, needs to be enabled. Moreover, we must all understand that participation needs not to be based solely on cooperation and may need to be confrontational and that it is up to the affected populations to choose their own strategy. But, fundamentally, participation means ensuring that governments, NGOs and intergovernmental agencies are accountable. I am afraid that until affected persons do not have a voice and choice, achieving the NTDs and SDGs framework will keep slipping through our fingers.