**Response to Questionnaire for Non-Governmental Organizations**

**Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and Their Family Members**

Founded in 1994, IDEA is the first international advocacy organization whose leadership and membership is composed of individuals affected by leprosy. With members in more than 30 countries, we focus on human rights, advocacy and empowerment. IDEA’s *Quest for Dignity* exhibit which presents individuals’ experiences with leprosy through dignified images and inspiring quotes, was officially launched in 1997 at the United Nations by Secretary General Kofi Annan. IDEA has been an NGO in Special Consultative Status with the Economic and Social Council of the United Nations for nearly 10 years.

Below are the answers to the questions.

1. We were involved throughout the development of the Principles and Guidelines, from gathering information from IDEA branches in various countries that was the basis of a position paper submitted to the Human Rights Council Advisory Committee, to providing feedback to the Committee on drafts of the Principles and Guidelines at different stages.
2. Dr. P.K. Gopal, the IDEA Representative for India and one of IDEA’s Presidents, is familiar with the national government of India’s discussions to disseminate the Principles and Guidelines. We are not familiar with actions taken by any other governments.
3. We are not familiar with any government actions in the area of policies, action plans or other measures related to the Principles and Guidelines.
4. Dr. P.K. Gopal has been involved in advocating for changes to discriminatory legislation in India over the past several years, and the national government has been addressing this. A legal advocate working with IDEA Nepal drafted a position paper on discriminatory legislation in Nepal that was to be addressed in the Constitution. With the lack of stability in the government, the status of this is currently unknown.
5. It is also important to bring into the discussion offensive terminology used by the media, as once it is seen in print, society may consider such language acceptable. Here are some current examples.

The words “leper” and “inmate” should not be used to refer to individuals with leprosy. <http://www.deccanherald.com/content/503865/lepers-begging-get-govts-tahirpur.html>

<http://www.ngrguardiannews.com/2015/10/lepers-protest-over-alleged-pay-cut-neglect-in-delta/>

<https://www.brnow.org/News/May-2015/Leper-prays-as-Nepal-earthquake-rumbles>

Likewise, photos that focus only on parts of the body with disability, or portray persons who have the disease as non-contributing members of society foster discrimination.

1. Since its founding in 1994, IDEA, through its Board of Directors (75% of whom have had leprosy) and IDEA Representatives in various countries (90% of whom have had leprosy) actively receives input on its philosophy, mission, goals, and priorities from persons who have experienced leprosy. IDEA Representatives work with people in their community who have had leprosy, to identify priorities for their region and/or country.
2. We are not familiar with government measures in this area.

However, IDEA members advocate themselves on behalf of persons affected by leprosy. In addition to the work of Dr. Gopal in India, members of IDEA Nigeria have met with local government officials to ensure equal education for their children living in leprosy communities, as well as request initial funding for economic projects. Described under question #15 is another example of advocacy in Nigeria undertaken by people who have experienced leprosy. IDEA Ghana is coordinating a program--without government assistance--for people separated for decades from their family and community, helping these individuals to return home.

1. We are not aware of any government measures.
2. We are not aware of any government actions.
3. We are not aware of any government actions. IDEA however, has developed media guidelines that we share with the various media representatives including writers and photographers as well as NGO’s.
4. We are not aware of any Government plans to adopt a national action plan.

IDEA believes however, that the Principles and Guidelines should not only be implemented beginning with national governmens. People themselves should also be made aware of their rights, beginning at the local level. As individuals' awareness and understanding of their rights as outlined in the Principles and Guidelines increases, the Principles and Guidelines can become an effective tool to help individuals advocate for their rights, thereby promoting inclusion in society. Through IDEA, we have seen the effectiveness of people who have experienced leprosy advocating for themselves at local, national and international levels.

1. As we are not aware of any Government plans to adopt a national action plan we are unaware of obstacles.
2. This is complicated as there are so many variables. Governments are over burdened with other health priorities, crises-both known and unanticipated, and regulations. Resources vary from country to country. Perhaps a mechanism tied into an already existing monitoring mechanism for another illness or form of discrimination can be developed. Partnerships with NGOs involved in the field of leprosy or with organizations of persons affected by leprosy should be considered in this process.
3. See question #15.
4. In Nigeria a man who had paid for a Hajj, was denied a passport by the Nigerian immigration service because he had had leprosy. (He was cured but had visible disabilities as a result of the disease.) IDEA Nigeria met with the controller general of immigration on this individual’s behalf and this man was given a passport. Additionally, the controller general of immigration immediately made all States aware of this issue to prevent a future recurrence.