

INTERNATIONAL SYMPOSIUM:

TOWARDS HOLISTIC CARE FOR PEOPLE WITH HANSEN'S DISEASE, RESPECTFUL OF THEIR DIGNITY

Vatican City, 9-10 June 2016

Conclusions and Recommendations

The International Symposium on the topic, “Towards Holistic Care for People with Hansen’s Disease, Respectful of Their Dignity,” was jointly organized for June 9 to 10, 2016, at Vatican City by the Pontifical Council for Health Care Workers, the Good Samaritan Foundation and the Nippon Foundation in cooperation with the Fondation Raoul Follereau, the Sovereign Order of Malta and the Sasakawa Memorial Health Foundation. These Conclusions and Recommendations were presented at the end of the two-day symposium and were approved in principle by the organizers and the participants who were present.

Note: While the terms “Hansen’s disease” and “leprosy” are used interchangeably in this document, in some countries the preferred term is Hansen’s disease.

Conclusions:

1. ***Every new case of Hansen’s disease is one case too many.*** It has been observed that new cases of Hansen’s disease are on the decrease and we should be very happy about this. But this decrease, which is in itself positive, could have resulted from *a decline in case-finding activities and reduced community awareness*. The increase in the rate of disabilities in new cases detected seems to support this explanation. Therefore, it is essential *to aim at early detection*. This applies to all new cases, *but particularly to child cases*. The WHO’s Global Leprosy Strategy 2016-2020 is moving in this direction. A second cause for concern comes from the substantial *risk of partly losing the expertise* that has been accumulated over recent decades by leprosy experts, medical doctors and health workers in relation to Hansen’s disease. Grants for study and training may be needed for service providers and caretakers including persons affected by the disease. Here, the principle, “Nothing about us without us” should be respected, and this is an important way of fighting against the stigma that is associated with Hansen’s disease. A number of valuable recommendations in the presentations concerned methods to improve early diagnosis and promote the social integration of persons affected by leprosy. Public and private institutions should work in close cooperation with health authorities in each country to provide medical and health personnel with basic education about leprosy in

order to strengthen leprosy programs within the framework of general health services. Efforts should be made to reintegrate communities of persons affected by leprosy into society. The message that leprosy is curable and can be treated while the patient continues to live at home should be emphasized.

2. *Every case of stigma and social exclusion is one case too many.* Stigma is often associated with a religious vision of life and it would be advisable to revise this belief. In reality, stigma has been linked from the earliest times with fear of a disease that cannot be defeated. Biblical texts of the Old Testament themselves record a practice of exclusion that was present in Egyptian, Assyrian-Babylonian and Canaanite cultures during the second millennium before Christ. The same fear is to be found in non-Christian and non-religious contexts. The teaching of Christ in the New Testament, first of all, *breaks, with great clarity, the connection between illness and sin* (John 9:2-3). Secondly, *Jesus Christ touches people with leprosy, enters into contact with a sick person without any fear of contagion or impurity, and heals and reintegrates people into the community.* Even more, he himself accepts being treated as if he had leprosy. The example of Christ has often not been followed—this neglect enables us to understand that it is easier to eliminate the disease at a medical level than the social prejudice that surrounds it. In this sense, it is absolutely necessary that we place the human being at the centre of all medical activity, rather than, as is often the case, placing the disease at the centre of attention.

It is the teaching of Christ which has led Christians, especially over the last two centuries, to develop a high level of care and treatment for people with Hansen's disease. This took place even before pharmacological therapies were available, when care involved accepting and rescuing people and ending their state of abandonment. There is no need to recall here the giants of charity who were dedicated to this service. Today, as well, the Catholic Church remains strongly committed in almost all countries where the disease is found, to providing medical and humanistic care. Here a pathway opens up of cooperation with religious communities of other faiths and with all men and women of good will.

It is the shared opinion of experts who work in the field of Hansen's disease that the elimination of the stigma attached to leprosy requires an important work of education that must involve all social groups and in particular religious communities because they promote respect for human dignity throughout the world.

3. *Every law that discriminates against people affected by Hansen's disease is one law too many.* Following intensive work, the General Assembly of the United Nations in December 2010 adopted a resolution on Elimination of discrimination against persons affected by leprosy and their family members, accompanied by 'Principles and Guidelines'. The resolution and 'Principles and Guidelines' constitute a *milestone in the upholding of the human rights of*

persons affected by Hansen's disease. One must take into account that for every person with the disease, his or her family members and even relatives may also be ostracized due to the stigma attached to leprosy, resulting in a serious violation of fundamental human rights. An enormous amount of work still has to be done by governments and social and religious institutions to ensure that these 'Principles and Guidelines' are fully implemented.

Unfortunately, various forms of discrimination continue to exist in many parts of the world which bear upon all spheres of life: schools, workplaces, social groups, public places, religious centres, restaurants, hotels, trains and other means of transport. Especially grave are the violations of the rights of persons affected by leprosy in the field of education, work, and marriage. The necessity to repeal discriminatory laws that impede fundamental human rights is very urgent and can no longer be postponed.

Implementation of the 'Principles and Guidelines' requires constant work involving the sensitisation of governments and societies. To this end, in 2012 the Nippon Foundation created a working group (the International Working Group, hereafter IWG), *which had the aim of assisting the process of implementation of the 'Principles and Guidelines'*. The IWG prepared a "Suggested Framework for National Plans of Action" for States to use in their own domestic contexts.

The IWG came to the conclusion that the 'Principles and Guidelines' were more likely to be effective if States were called upon *to undertake specific ways of implementing them*, which could then be brought to the attention of various governmental offices and communicated to relevant UN bodies, specialized agencies, funds and programmes, other intergovernmental organizations and national human rights institutions. To this end, the IWG recommended *the institution of a follow-up mechanism* at an international level which would have the mandate to follow up the actions of States and other stakeholders, drawing upon the experience of Special Rapporteurs on various topics of human rights appointed by the United Nations Human Rights Council, or committees of experts which monitor the implementation of international human rights treaties and conventions. This follow-up work must not be neglected, otherwise there will be no perception of progress or steps back.

Accordingly, in the Resolution adopted by the UN Human Rights Council on 2 July 2015, the UN Human Rights Council Advisory Committee is requested to submit a report containing practical suggestions for the wider dissemination and more effective implementation of the 'Principles and Guidelines' at the 35th session of the United Nations Human Rights Council in June 2017.

The IWG has observed, in particular, the need for civil society and religious communities to use dignified terminology when speaking about Hansen's disease. It has been observed that the old perceptions of leprosy continue to be reinforced by inappropriate language. The offensive term 'leper' as a description of someone with leprosy evokes a marginalised person, a sinner, or a person who is rejected by other people for moral or social

reasons. This terminology contributes to discrimination against persons affected by leprosy and even discourages those who need treatment from seeking help. The IWG has thus invited religious leaders and their communities to reflect upon the best ways of expressing themselves in language that is able to transmit respect for persons affected by leprosy. Awareness-raising activities at the global level should make full use of new media to inform people about advances in treatment of leprosy and the fact that people who are under treatment or have completed treatment are not infectious. It is important that this information is available even in countries where leprosy is not an issue, in order to eliminate the myths surrounding this disease.

Final Recommendations

Two Introductory Points

1. Persons affected by Hansen’s disease must be seen as the main actors in the fight against this disease and the discrimination it causes. This involvement is a powerful instrument for the recognition of their equal dignity and rights for social inclusion, and for the breaking of the stigma attached to them. This point applies to all of the recommendations listed below.

2. The use of discriminatory language that reinforces stigma must cease, in particular, use of the term ‘leper’ and its equivalent in other languages. This term is offensive for the reasons stated above and also because it defines a person by his or her illness. Use of the term “leprosy” in a metaphorical sense should be avoided.

Five Recommendations

1. Given their important role in their respective communities of believers, the leaders of all religions—and this is an important and urgent matter—should, in their teachings, writings and speeches, contribute to the elimination of discrimination against persons affected by leprosy by spreading awareness that leprosy is curable and stressing that there is no reason to discriminate against anyone affected by leprosy or members of their families.

2. States and governments should be encouraged to make great efforts to implement the ‘Principles and Guidelines’ accompanying the resolution adopted by the General Assembly of the United Nations in 2010 on Elimination of discrimination against persons affected by leprosy and their family members. These ‘Principles and Guidelines’ must be fully implemented, otherwise they will remain just empty proclamations.

3. There should be a modification or abolition of all laws and regulations that discriminate against persons affected by leprosy. Policies relating to family, work, schools, or any other area which directly or indirectly discriminate against persons affected by leprosy must also be changed, recognising that no one must be discriminated against because of the fact that he or she has, or once had, leprosy.

4. There is a need for further scientific research to develop new medical tools to prevent and treat leprosy and its complications, and to achieve better diagnostic methods.

5. In order to achieve a world free of leprosy and the discrimination it causes, the efforts of all the Churches, religious communities, international organizations, governments, major foundations, NGOs, and associations of persons affected by leprosy which have hitherto contributed to the fight against this disease should be unified and joint plans of cooperation should be developed.