Learning from Leprosy

Medical & Human Rights Approaches to Stigma

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Leprosy in Society
Hay Ling Chau, Hong Kong
Leprosy in Society: The Relationship of the Social to the Medical Pathology of Leprosy

1) Externally manifest
2) Appear to be incurable
3) Progressively disabling
4) Non-fatal and chronic
5) An insidious onset
6) Fairly high endemicity, but not be epidemic
7) Incidence rate associated with a low standard of living
8) Long incubation period
“Through the light of understanding of the genesis of the social reaction, we should challenge society with rational understanding of its irrational fear.”

-- O.K. Skinsnes
The development of MDT should render the first three characteristics moot – the disease no longer needs to be externally manifest, disabling or regarded as incurable.
The fact that there is still a strong social response to leprosy 70 years after the discovery of a cure and 30 years after the introduction of MDT shows that looking at leprosy primarily through a medical and scientific lens is not enough to solve the complex medical and social issues associated with this disease.
Human Rights Approach

Places the responsibility for the stigma on society, not on the individual

Bacurau - Brazil
The Human Rights Approach looks at the negative social response/stigma as a fundamental violation of people’s rights.
“Looking at leprosy through the lens of human rights reaffirms the inherent dignity that is the birthright of every individual.”

-- U.N. Secretary General Kofi Annan, at the Opening of the Quest for Dignity Exhibit at the United Nations, 1997
“We refuse to allow others to define ourselves, our humanity, by a disease.”

Bernard K. Punikai‘a
International Human Rights Advocate
Composer, Musician

Bernard Punikai‘a speaking at the United Nations, 1997
First International Conference on Issues Facing Women Affected by Leprosy

Women’s Rights National Historical Park -- Seneca Falls, New York, 2002
2003 – IDEA Global Campaign to Eliminate the Stigma – Promote the Light of Understanding

Acknowledge that the stigma can be eliminated
Expand the International Network of Support
Robben Island Conference

Facing History and Ourselves – Teachers’ Workshop
“We believe that a person who feels dignity will not allow anyone to negate their rights.”

-- IDEA’s First Latin American Women’s Workshop
Ensure Adequate Support & Counseling
Promote Opportunities for Education & Economic Independence
Transform the Social Image of Leprosy by Promoting a Positive Image
... and Emphasizing The Legacy of Creativity
Build Bridges Towards Universal Human Rights & Peace
Use the Wisdom of the Older Generation to Effect Social Change

Olivia Breitha

Lu De Chang

Yasuji Hirasawa
&Generate The Light of Understanding