Stigma, Identity and Human Rights
The Experience of Leprosy in the Era of HIV/AIDS
An International Conference on Robben Island, South Africa

“The place where we are now, it used to be a prison. We visited some of the graveyards of our brothers and sisters who were placed here as a result of discrimination, but with the rights that we have today, we were all there making prayers for the past, for the present and for the future. This is human rights.”

-- Jaime Tomas Cabeto, ARPAL/IDEA Angola

“The question is -- is the stigma ever going to end? That's the question I ask myself every day . . . . We must stand up, we must break the silence and speak out . . . . So, women, men, with HIV/AIDS or leprosy, let us stand up and fight together, and fight these diseases and fight stigma and discrimination.”

-- Mimi Badamuti, Sinikithemba HIV+ Choir, South Africa

Photographs: Clockwise from top right: Mimi Badamuti places a shell lei on the grave of an unidentified individual who was isolated on Robben Island due to leprosy. Erna Moller, The Leprosy Mission South Africa, holds the South Africa panel that remembers five individuals who had leprosy and made important contributions to history and humanity. The IDEA Banner of Honor is displayed at the cemetery on Robben Island where individuals who had leprosy were buried. Inspired by the AIDS Memorial Quilt, the IDEA Banner of Honor recognizes individuals who have had leprosy who made significant contributions to their communities, their countries and the world. Photos by Henry Law
The Indestructibility of the Human Spirit of Resistance Against Colonialism, Injustice and Oppression

“Robben Island represents the triumph of the human spirit against adversity. What does it mean for the spirit to triumph? One of the ways in which we have interpreted it is that we triumph through resistance; that an act of resistance against oppression, an act of resistance against stigma, an act of resistance against segregation, is a triumph of the spirit.”

-- Deirdre Prins Solani, Manager, Education Department, Robben Island Museum

From February 4-6, 2005, individuals from 16 countries whose lives have been impacted by stigma, either as a result of leprosy or HIV/AIDS, joined in discussion with historians and other individuals specializing in issues related to leprosy, HIV/AIDS and human rights. The powerful backdrop of Robben Island, an international symbol of (in the words of the Robben Island Museum) “the indestructibility of the human spirit of resistance against colonialism, injustice and oppression”, inspired discussions of how history can effect social change. At the same time, the legacy of Robben Island and all those who resisted its oppression empowered discussions on how stigma denies both identity and human rights, with a view to developing concrete actions that can be used towards eliminating the power of stigma to destroy people’s lives.

“From the age of 14, my life was as ‘leprosy patient Miyoji Morimoto’ and I was never able to live as Miyoji Morimoto alone. This is something that I still hold in my heart.” -- Miyoji Morimoto, IDEA Japan

“When you came into prison, your name was written down into a book and you were given a number . . . . You lost your name, you lost your identity, your sense of belonging. So there was an attempt to erase an identity . . . . When we fight against oppression and segregation and we fight against erasure, the voices of people who have experiences of a particular condition should be the people who speak. And that’s why when we learned who the participants in this workshop were, we were very excited. We said, yes, this is in keeping with the mission of this institution.” -- Deirdre Prins Solani
A Common Understanding, A Common Journey

“Coming to Robben Island . . . you met people who had a common understanding, a common journey, and destiny like you. Robben Island was a learning institution. The first morning here, it was kind of cold, and a guy said to me, ‘You’re home now. You’re not going to live tomorrow, you’re not going to live yesterday, you’re going to live today and today only. Now look around. You’ve got brothers, you’ve got fathers, you’ve got uncles, you’ve got everything you need. Whatever you need, approach any one of us.’ And, I felt safe for the first time and that I was among human beings again . . . . at the end of the day the slogan here was ‘each one, teach one.’”

-- Eugene Mokgoasi, former political prisoner and currently an interpreter on Robben Island, who was arrested at the age of 16 and released at the age of 26.

“When I met Bacurau in Rio De Janeiro, it was a cold, rainy evening. He pointed at a child who was covered with newspaper sheets on the street and he also pointed to a car that had a rain protection cover. And he said that we were supposed to fight against any form of social injustice. Because the same situation, the same conditions that cause leprosy discrimination, were the same conditions that made our society protect a car more than a child.”

-- Artur C.M. De Sousa, MORHAN, Brazil, remembering Francisco A.V. Nunes, “Bacurau”, the founder of MORHAN (Movement for the Reintegration of Persons Affected by Hansen’s Disease) and IDEA’s first President for International Advocacy.
What I Wish . . . . Is That I Can Have My Freedom

“What I really wish to ask the Government is that I can have my freedom. I do not wish to complain of anything else but the loss of my freedom . . .”

-- Frans Jacobs, who was sent to Robben Island on December 10, 1886 at the age of 35 because he had leprosy, in a statement made November 14, 1892. Western Cape Provincial Archives. Frans Jacobs is remembered on the IDEA Banner of Honor. [References to Frans Jacobs' correspondence courtesy of Dr. Harriet Deacon, and also Richard Whiteing, Robben Island Museum.]

“The main idea of the absolute segregation policy in Japan was to abolish and eliminate the patients. It was not to cure them. I was diagnosed with leprosy in 1947. I was shunned by society and segregated in a sanatorium on an isolated island. There, I was forced to wait for my life to end . . . . After 21 long years, I finally returned to society.

“In Johannesburg, I went to an Apartheid Museum. There I saw the history of the people who were put in jail for no reason other than being black. That particular image overlapped with my own experience. In this sense, apartheid, the Japanese segregation laws and segregation policy, were similar. One was for racial discrimination and the other was discrimination against those people who had leprosy.”

-- Ryohei Shibata, IDEA Japan

“At Westfort (a leprosy hospital that’s just outside of Pretoria) from about 1890-1948, one of the themes that I constantly find is that the authorities tried to segregate and oppress people by gender, by race and by their disease. They were constantly trying to segregate them to take away their identity. Yet, it was very clear that people fought against that . . . .

“Yesterday there was a talk about the political prisoners signing their names and it’s the same with Mr. Pipe who was at Westfort . . . . a man who wrote to the newspapers, not as a person affected by leprosy, but as a person . . . . There were a number of occasions where the women patients, for example, had a sit down strike and refused to work until they were called by their names . . . .”

-- Simonne Horwitz, Wellcome Unit for the History of Medicine at Oxford. Mr.Pipe is remembered on the IDEA Banner of Honor.
**Resistance: Retaining Identity in the Face of Oppression**

“I have a Day school and a Catechising School, also an English School and the people are progressing right well. I will select an Under schoolmaster soon. I have my hands full; but if God spares me I think in the course of a year several will be able to write their own letters.”

-- Frans Jacobs to Henry De Smidt, Under Colonial Secretary, September 8, 1892. *Western Cape Provincial Archives*

“With the 1892 rebellion led by Franz Jacobs, there was active resistance against institutionalization on the island. The way in which Franz Jacobs’ rebellion was silenced is interesting. There is almost nothing in the colonial archive here in Cape Town about the rebellion. The only place I’ve found any record of it was in London in the Public Records Office. It has been wiped off the face of the colonial archive . . .”

-- Dr. Harriet Deacon, Robben Island Historian; Consultant, Human Sciences Research Council, Cape Town

“When I remember 39 years back, my life was turned upside down. After facing repeated discrimination, I started to drink; I was a chain smoker. One day I thought, ‘What am I doing?’ So I started to think beyond my disability, beyond stigma, beyond the disease. I started to resist. I helped found ENAELP, the Ethiopian National Association for Persons Affected by Leprosy and also the Ethiopian Federation for Persons with Disabilities . . . .

“We have to resist social stigma, discrimination, isolation . . . . Our colleagues, our companions on Robben Island from 1846-1931, they were fighting alone here on this island. Now we are united and this gives us strength.” -- Arega Kassa Zelelew, IDEA Ethiopia
The Stigma That Resides In Society

“Stigma shouldn’t be seen as residing in the individual with a disease, but it resides in the society that has not found a way to be inclusive. We have a duty to diagnose and treat this stigma.”
-- Dr. John Manton, Wellcome Unit for the History of Medicine at Oxford, U.K.

“When you talk about the laws related to leprosy, what you’re really talking about are the laws of silence. People were not speaking out about the injustices of banishment for those persons affected by leprosy in the last 3,000 years. It has only been very, very recently that this has occurred.”
-- Jose Ramirez, Jr., IDEA USA

“People who had been slaves, whose ancestors had been slaves, felt they carried a stigma of slavery . . . . What slaves were deprived of were their names, their families, their languages . . . . [and] perhaps most importantly of all, their histories. So part of the struggle against slavery and within slavery was to recover a history. Integral to the struggle against slavery was always the telling of stories . . .”
-- Professor Megan Vaughan, University of Cambridge, U.K.

“Ignorance becomes a barrier for people to help other people. We are trying right now to educate people, to make them aware, to share our stories.” -- Bhekani Memela, Sinikithemba HIV+ Choir, South Africa

“For me, I can trace my family history all the way back to a small fishing village in Spain. That is very important to me and to my family although it’s not important to anyone else. When a person is diagnosed with leprosy oftentimes that person’s history is taken away because of banishment, whether it’s through laws or through practices of different countries. There’s also the history that is taken away when our families feel that we’re no longer worthy of being a part of their family. If you look at all of this collectively, the stigma throughout the world becomes a very powerful force.” -- Jose Ramirez, Jr.
The Triumph of Freedom and Human Dignity

“To us, freedom meant the year of restoration of your dignity, the year of peace, the year of respect, the year of rights.”

-- Paul Langa, Former political prisoner, Chief Executive Officer, Robben Island Museum

“Human rights are not abstract nor only the result of legislation or public statements. They refer to the respect for the individual as a person, for his or her dignity, and the right to pursue his or her life.”

-- Professor Bernardino Fantini, Director, Institute of History of Medicine & Health, University of Geneva, Switzerland

“We want Robben Island to reflect the triumph of freedom and human dignity over oppression and humiliation.”

-- Ahmed Kathrada, Chairperson of the Robben Island Museum Council, who was Prisoner 468/64 on Robben Island from 1964-1982.

“Freeing ourselves of prejudice, Take a soar into the wind.”

-- Nanahuku Ikuta, Japan

Left to right: Saruto Labbo (IDEA Nigeria), Chamada Abibo (IDEA Mozambique), Alhaji Shehu S/Fada (IDEA Nigeria) and Miyoji Morimoto (IDEA Japan) in front of an exhibit on Robben Island that recalls the words of Ahmed Kathrada.

Photo by Pamela Parlapiano
“Despite our hopes, stigma and discrimination surrounding leprosy are still with our people. They have accumulated throughout history and will not go away in such a brief space of time.

“Bacurau from Brazil once said, ‘When a person dreams a dream alone, it is only a dream. But when that dream is shared by others, for certain that dream will come true.’ When I think of his words, as I think of my own life, the words attain a certain ring of truth.

“The dream that we all dream will, for certain, come true, just as there are no days that the sun does not come up.”

-- Ryohei Shibata, IDEA Japan

[Note: For more photographs and excerpts from the Robben Island Conference, see www.idealeprosydignity.org]