

## Inclusion is a Matter of Justice

*Inclusion is a matter of justice and equality of rights. We believe that human rights come from the heart of people and they must come from the heart of the nations.*

-- Zilda Borges, Brazil, IDEA's President for International Advocacy

*Our mission is to develop strategies that can add value to each person as a whole.*

-- Ymelda Beauchamp, IDEA USA; Board Member, ALM



Participants in the WHO Meeting on Developing Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Services, held in Manila, Philippines, June 9-10, 2010. Half of the experts invited to participate in the meeting were people who had experienced leprosy themselves.  
*IDEA Photo*

## Ensuring the Right to Equal Participation Equity, Social Justice, Human Rights



“States should promote, protect and ensure the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination . . . ”

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



(Top) Flags at the United Nations in Geneva; (Bottom, left to right) Kofi Nyarko, Zilda Borges and Dr. P.K. Gopal visit the World Health Organization Headquarters in Geneva in 2009, while participating in discussions at the United Nations on leprosy and human rights.



The United Nations, Geneva, Switzerland, 2004: (Left to right) Mr. Yohei Sasakawa, President of The Nippon Foundation; Dr. P.K. Gopal and Zilda Borges, current Presidents of IDEA, with portions of the *Quest for Dignity* Exhibit. Pictured in the Exhibit is Francisco A.V. Nunes, "Bacurau," who spent his life working to ensure the human rights of every individual. *IDEA Photos*

In December, 2010, the United Nations adopted Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and Their Family Members.

During the process of the formulation and finalization of these guidelines, which lasted several years, IDEA applied for and was granted Special Consultative Status with the Economic and Social Council of the United Nations, which includes the Human Rights Council.

In 2010, the World Health Organization developed Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Services.

This newsletter highlights some of the ways in which people who have experienced leprosy have been involved in areas outlined by the UN Principles and Guidelines and the WHO Guidelines.

## Stigma and Discrimination

“The only way to get over stigma and prejudice is within yourself. You have to first get over it within yourself. It is something that is very personal.”

-- Cristiano Torres, MORHAN, Brazil

“Internal stigma, I believe, is not because we have done anything wrong . . . It comes about because of what I call the law of silence . . . When a group of individuals, a community, a nation, turns away and refuses to acknowledge that the rules of isolation are objectionable, the silence leads some of us to believe internally that those stigmatizing attitudes and practices are OK.”

-- José Ramirez, Jr., USA

“People affected by leprosy in each country should be encouraged to collect and record their own histories. By recording complete histories of the lives of persons affected by leprosy, we can turn the negative legacy so often portrayed by the media into a universal message of hope and triumph.”

-- Fontilles Resolution, Spain, 1997



Cai Ping, at the 10th anniversary celebration of HANDA/IDEA China in 2006. *Photo by Henry Law*



An oral history interview is conducted in 2005 with Enarion Cripakau, who was 78 at the time and had resided at Tichilesti, the last leprosy hospital in Romania, for 63 years: “I haven't lost my passion for gardening. When you garden, you leave something for others.” *Photo by Henry Law*

“I wrote a book because I wanted people to know what I feel, what I felt . . . How much I struggled, fighting the disease, fighting bureaucrats, trying not to be a statistic, trying to be a person.”

-- Olivia Breitha, Hawaii, author, *Olivia: My Life of Exile at Kalaupapa*

“A few years ago there was a river that went by our village and we were not allowed to use that water. If we wanted to buy something, we could not buy from the nearby villages. One person used to have to go far away to buy things for us. Now we don't need to go far away to buy things anymore. In fact, the person who used to go to buy things for others lost his job. We can now buy things for ourselves. Now some people even come to our village to sell to us.”

-- Cai Ping, P.R. China, speaking about the changes in his village due to the efforts of HANDA, IDEA China

## Planning & Management of Services Training & Capacity Building

*People affected by Hansen's disease do not need charity, but the opportunity to show we are capable and, in so doing, perhaps change the world.*

-- Cristiano Torres, MORHAN, Brazil

“The involvement of persons affected by leprosy in key activities of leprosy control services has long been considered essential. Yet it has received scant attention. There has been a lack of awareness among policy makers about the importance of including those individuals for whom the services are designed, as well as recognition of the significant contributions that people who have experienced leprosy have already made to their communities and the world . . . Ensuring that persons affected by leprosy are the central focus of programs will have profound implications for the way that services are planned, delivered and evaluated.”

-- WHO Guidelines on Strengthening Participation of Persons Affected by Leprosy in Leprosy Services



Participants in the WHO Meeting in Manila: (Left to right) Michihiro Koh, Japan; Dr. P.K. Gopal, India; José Ramirez, Jr., U.S.A.; Sophea Leng, Cambodia; Adi Yosep, Indonesia; Binti Khoiffah, Indonesia; and Kofi Nyarko, Ghana. *IDEA Photo*



(Left to right) Kofi Nyarko, Ghana; Ngoma Ngoma, D.R. Congo; and Abdou Yohanna, Niger, participate in a Training Session on Eliminating Stigma at the 17th International Leprosy Congress, India, 2008. *Photo by Henry Law*



(Left to right) Yiang Xiaoyuan, Zhao Yuanbiao, Hu Shouming, Guo Zhaohuan, and Ma Tiexi, receive the 2003 Handa Award for leadership and significant contributions to their communities. These men have not only worked to improve their own lives, but have also shared their knowledge and expertise with others. *Photo by Henry Law*

## Advocacy



Cristiano Torres speaks at the 17th International Leprosy Congress in India, 2008. *Photo by Henry Law*

“We used to say that if society changes, we will be able to change. We should discard this attitude and adopt the belief that society will change because We Ourselves Change. Let us believe this and make our lives rich and rewarding.”

-- Miyoji Morimoto, Japan

“We started to empower the general public in 2003. Because many people do not have televisions or radios, they need to be reached personally . . . we went camp by camp, church by church, school by school, village by village, educating people about stigma and discrimination, raising awareness, and talking about social justice and human rights.”

-- Kofi Nyarko, Ghana



Alhaji Shehu S/Fada (right), Chairperson, IDEA Nigeria, with Abakar Mohammed, IDEA Sudan 2007. *Photo Courtesy IDEA Nigeria*

“. . . the money we took from our savings box we used to register IDEA Sudan. We felt we should start IDEA without getting something from the outside . . . When Shehu came to us and talked to us about IDEA, then we said that this should not only work in Khartoum, but extend to all our brothers in Darfur.”

-- Abakar Mohammed reflecting on the beginnings of IDEA Sudan following an Expert Exchange visit from Shehu S/Fada, IDEA Nigeria

## Resource Mobilization

“Exclusion of people with leprosy has been taken for granted in the cultures, religions and languages of society for generations . . . One key to reversing the historic exclusion is to identify as many partners as possible and work with them aggressively . . . Developing partnerships is a key factor in eliminating stigma.”

-- Arega Kassa Zelelew, Ethiopia

“With the presentation of the funds from our small voluntary group called ‘A Drop of Grain,’ she expressed her deepest gratitude and gave us her blessing, saying, ‘This is one of the most precious donations I have ever received.’”

-- Miyoji Morimoto, Japan, recalling his meeting with Mother Teresa



Mr. A. Prakasam and his wife, Saroja. Mr. Prakasam has raised funds for IDEA International and assists with the IDEA India Scholarship Program. *IDEA Photo*

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## Counseling

“For those of us who’ve had leprosy, we have the ability to be good counselors because we have an important element and that is our own experience. We have experienced a lot of things that can help us to understand other persons and also help them to grow. As counselors we give our own being. With this kind of help we try to help people to recover a feeling of dignity, security and belief in themselves.”

-- Graciela Baéz Benitez, Paraguay



Zilda Borges with Benedito Pereira. Photo by Pamela Parlapiano

“When we see people disheartened, dependent, without perspective of change, something of their essence has been taken from them. In the case of leprosy, the historical behavior of people not affected has robbed the essence of a dignified life for people affected by leprosy. Thus, there has to be a lot of patience. To recuperate the essence of life is a skill, and we have to count on all the difficulties and maintain the hope of always beginning again.”

-- Zilda Borges, Psychotherapist, Brazil



Nevis Mary talks with a mother at a leprosy village, Raipur, India. Photo by Henry Law

“In 2003, IDEA gave me a platform to come out of my shell, to come out of the burden of secrecy in my heart. So that day I cannot forget . . . I, too, started giving counseling, especially for women.”

-- Nevis Mary, India, reflecting on IDEA India's First Women's Empowerment Workshop

“The ability to listen to another person means to make silent your own beliefs and moral values. To be able to accept the other person without conditions, without judgment about what they think, what they say, what they do.”

-- Graciela Baéz Benitez, Paraguay

## Gender Issues



Participants from Nepal and India at IDEA Nepal's First Women's Empowerment Workshop, 2006. *Photo by Pamela Parlapiano*



Participants in the First International Conference on Issues Facing Women Affected by Leprosy, Seneca Falls, New York, 2002: (Left to right) Satono Hamamoto, Japan; Yashoda Jirel, Nepal; Grace Akandoh, Ghana; and Bhim Kumari Gurung, Nepal, at Women's Rights National Historical Park. *Photo by Henry Law*

“We believe that a person who feels dignity will not allow anyone to negate their rights.”

-- IDEA's First Latin American Women's Workshop, 2006

“We all know that gender issues do not hold back just women . . . If you educate a woman, you educate a community.”

-- Ymelda Beauchamp, USA



Yohana Yahua, Member of IDEA Mozambique and Coordinator of the ALEMO Women's Program, 2005. *IDEA Photo*

## Information, Education & Communication Referral



Alhaji Shehu S/Fada (left) from Zamfara State, Chairperson, IDEA Nigeria, with Aminu Usman from Katsina State at an Empowerment Workshop in Nigeria, 2003. *Photo by Pamela Parlapiano*

“It is time to consider ourselves partners in the delivery of basic information and knowledge. Our testimonies and success stories are the best educational tools. We can encourage others to seek early treatment, teach prevention of disabilities, assist in early diagnosis and referral, and be a support group.”

-- Ernesto Cabanos, Jr., Philippines

## Physical and Socio-Economic Empowerment



Sang Kwon Jung speaks on Korea's successful experience at the 2010 World Forum on Hansen's Disease in South Korea. The World Forum was organized by The Hanvit Welfare Association (formerly The Hansung Cooperative Association) and the Government. *Photo by Sigurd Sandmo*

“The Hansung Cooperative Association, was authorized as a legal social organization by the government in 1975. We started by keeping internal order and instructing people in raising livestock as well as exchanging information between those affected by Hansen’s disease. The Hansung Cooperative Association became an influential power through which we could speak out about our rights to the government. It was this start that made it possible for me to advance economically over the next 30 years.”

-- Sang Kwon Jung, South Korea, IDEA's President for Socio-Economic Empowerment

“We shall rely on ourselves rather than others. The welfare from the government is limited, and the help from relatives and friends is limited. Dependence on aid and sympathy will aggravate the social discrimination. Only if we become self-confident and mutually supportive, can we receive social recognition and believe in ourselves.”

-- Tiexi Ma, P.R. China



Mr. Laxmanan has a successful business on the road to a hill-top temple in Coimbatore, Tamil Nadu, India. *Photo by Henry Law*

*Publication of the IDEA newsletter is made possible through a grant from the Sasakawa Memorial Health Foundation*

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