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


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

“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
**Advocacy**

“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

“. . . 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
Counseling

“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

“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

“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

Information, Education & Communication Referral

“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

“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