The Right to Be Called By Our Own Names

The Establishment of IDEA in Angola and Mozambique and IDEA Participation in the African Leprosy Congress

“We will call each one by our own name with respect and dignity. We do not accept that we be called by the name of the disease or ill people after we have been cured. When we perceive that a person who was or is affected by leprosy is afraid or ashamed, we will approach that person, dialogue with him/her and accompany them with tenderness.”
-- Excerpt, Mozambique Declaration, 2005

Fatima Tarithe, IDEA Mozambique.

Mr. Picote and Mr. Lazare, with IDEA T-shirts saying “Illuminating Our Lives”.

Yahana Yahua, Member of IDEA Mozambique and Coordinator of the ALEMO Women’s Program.

“The workshop united us in heart with all the people in the world who were or are affected by leprosy and gave us the possibility of exchanging experiences and together seeking solutions to the problems that we face every day of our lives.”
-- IDEA Mozambique

Fifty-six individuals participated in IDEA’s Mozambique workshop, 53 from Mozambique and three international representatives. Photos by Zilda Borges
The Encounter Promotes Transformation

In August, 2003, Zilda Borges and Francisca Da Silva from Brazil traveled to Angola to help establish IDEA Angola, which also uses the local name ARPAL. Natália Isabel da Graça Marçals was elected President. In 2004, Natalia and Zilda visited Mozambique to introduce IDEA. In October, 2005, IDEA held its first empowerment workshop in Mozambique, where IDEA Mozambique was officially established. Three Presidents were elected: Chamada Abibo – President for Public Relations; Arone Juma Corado – President for Economic Independence; and Odete Saize – President for Human Rights and Women’s Issues.

Excerpts from Zilda Borges’ Report:

IDEA believes that the encounter between people who were or are affected by Hansen’s Disease transforms their hearts. The simplicity of a significant encounter sensitizes and makes us go forward, to love, to work and make some change.

It was with this spirit that as part of IDEA and as a person who has experienced Hansen’s Disease that I, Zilda Borges from Brazil and Natalia Marçal from Angola, traveled through some cities of Mozambique in February, 2004. AIFO and The Leprosy Mission were at our side, gathering the people affected by Hansen’s Disease so that an encounter could take place.

The encounter on this date with the people affected by Hansen’s Disease was not planned with a specific theme, it wasn’t a course or a talk. The most important thing was the lives of the people and what they had to say. As well as listening, to help to think of a possibility of change of attitude, we also shared the experience of a lot of people who had had Hansen’s Disease and who transformed life into possibility and potential. At this time we met people from Cabo Delgado, Nampula, Manica and Maputo.
Entering into contact with these people, I was very impressed with the position that those affected by Hansen’s Disease in Mozambique took in facing the world. For example, greeting people who were affected by Hansen’s Disease, I asked “How are you”? The majority replied “I am dead”. I kept thinking, how can people live as if they were dead? This fact made me recall the funeral rites that the Church administered in the transfer of a person affected by Hansen’s Disease to the leprosarium.

With people affected by Hansen’s Disease we couldn’t help but talk about the right to be called by our own name, the right to look after disabilities, to use adequate shoes and to take care of one’s own skin. Thus we wove dignity into that which can affect the essence of our BEING.

Natalia used to say:  *Human Rights begin within us. Therefore, we will call ourselves by our own name. We will look after our disabilities as a question of human rights.*

Natalia also asked:  *Let us help the older people to look after themselves. This is a question of solidarity.*

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.

In the end, the informal chats with so many people (145 approximately) affected by leprosy in Mozambique in 2004 were like rain on good ground. The people’s hearts were prepared to speak and to listen and that is what provided so many changes of negative attitudes to positive attitudes of life lived with dignity.

In 2004, we had met people from Cabo Delgado – there we got to know the Association ALEMO – whose motto is ALEMO - to give life. In fact, when greeting a person who participates in ALEMO if we asked: “How are you”? The person responded: “I’m alive”. We understood that the Association helps a lot to rescue dignity and to propose economic possibilities as a solution to being impoverished.

The Mozambique workshop in 2005 was a moment to gather fruit from the simple, small and significant encounters in 2004. It was with the joy of meeting again that we initiated the Workshop.

-- Zilda Borges, Brazil, Coordinator, IDEA’s International Womens’ Opportunities Program
IDEA Participation in the African Leprosy Congress
Johannesburg, South Africa, 2005

Arega Kassa Zelelew, IDEA Ethiopia, presents a paper on Developing Partnerships as a Means of Eliminating Stigma.

South Africa’s Minister of Health greets Rebecca Msimanga, IDEA, South Africa, with Zilda Borges and Saruto Labbo looking on.

Alhaji Shehu S/Fada, IDEA Nigeria, serves on a panel discussing leprosy and human rights.

IDEA sponsored a special session on “Defending Human Rights as an Alternative to Begging” with participants Crescenciano Rosello (Philippines), Dr. P.K. Gopal (India), S.K. Jung (South Korea), Kofi Nyarko (Ghana) and Alhaji Shehu S/Fada (Nigeria).

Kofi Nyarko, IDEA Ghana, discusses problems that result in individuals begging for a living in Ghana.

Dr. P.K. Gopal addresses the Congress on issues related to leprosy and human rights, together with Mr. Yohei Sasakawa.

IDEA Members display the IDEA Banner of Honor at the Opening Ceremony of the African Leprosy Congress. The panels are made by different countries to remember individuals who have had leprosy who have made important contributions to their communities, their countries and the world.

The Quest for Dignity Exhibit is displayed in the lobby of the Eskom Convention Center. Photos by Henry Law
Developing Partnerships as a Means of Eliminating Stigma

Excerpt from Paper Presented by Arega Kassa Zelelew at the African Leprosy Congress

Exclusion of people with leprosy has been taken for granted in the cultures, religions and languages of society for generations. Religions like the Orthodox Church and Islam have reinforced segregation and isolation in their teachings. Religious messages which relate leprosy to sin have prevented people affected by leprosy from developing partnerships within communities. Although correcting such distortions takes time, it is wise to appreciate that the problem is so serious that it cannot be left aside. One key to reversing the historic exclusion is to identify as many partners as possible and work with them aggressively.

When we established ENALEP, the Ethiopian National Association of People Affected by Leprosy, in the early 1990’s, we overcame initial resistance and were accepted as members of the Ethiopian Federation of Persons with Disabilities. Our association became part of this federation composed of associations having different shapes but with similar types of problems. In 1999, as a result of this partnership, individuals affected by leprosy participated in the sports festival for people with disabilities for the first time in the festival’s 27-year history.

Developing partnerships is a key factor in eliminating stigma.

A Grassroots Effort to Spread the Philosophy of IDEA

Excerpt from Paper Presented by Jackson Kofi Nyarko at the African Leprosy Congress

Many people in Ghana do not have radios or televisions, so need to be reached personally. IDEA Ghana has visited people affected by leprosy, region by region, community by community.

In the Ashanti region there is great stigma and we learned that many people have died as the result of discrimination. In Kofofu, a doctor said prayers for those who had died as a result of discrimination and donated 100,000 cedis for IDEA Ghana.

In the HO region, many people said they wished to stop begging and wanted us to take them to their hometowns and educate their communities. We were able to take some back to their hometowns.

From HO we moved to Kpandae and the northern regions of Ghana, where the people are suffering greatly with no good drinking water, scarce food, children unable to go to school, and poor housing made of wood and leaves. We spent some days here to show our feeling and concern for them. We then visited greater Accra.

Our visits have created a new spirit of hope in Ghana. Because of our teachings, some people have also started to say that our philosophy has helped those who have HIV/AIDS.
In 2005, from the 31st of October to the 3rd of November a workshop was held in Anchilo, of people who were or are affected by leprosy. Fifty three (53) people participated, coming from the Provinces of Cabo Delgado, Manica, Niassa, Zambezia and Nampula. The workshop united us in heart with all the people in the world who were or are affected by leprosy and gave us the possibility of exchanging experiences and together seeking solutions to the problems that we face every day of our lives.

We declare that:

• We will call each one by our own name with respect and dignity. We do not accept that we be called by the name of the disease or ill people after we have been cured.

• We will do everything in our power to help to educate society to change the language, to call people to dialogue, to clarify the importance of calling people who were or are affected by leprosy by their own name.

• When we perceive that a person who was or is affected by leprosy is afraid or ashamed we will approach that person, dialogue with him/her and accompany them with tenderness.

• We will struggle to be equal, to be law abiding persons just like any other citizen.

• We will not use our disabilities to ask help from others. We will try to develop our potential and form partnerships with a proposal for work.

• In confronting discrimination and exclusion, we will take on an attitude that will help to change human relations. The discrimination can be in our hearts and in the hearts of others. Discrimination is a personal and social pain. We want to help to cure this pain.

• We will fight with all our strength to avoid isolation and integrate ourselves, with heads held high, into Mozambican society.

• Little by little we will overcome the economic difficulties and the difficulties to develop any type of work because of disabilities. In this sense, we will stimulate the creation of micro projects of income generation according to the physical possibilities, involving the family. Little by little we will overcome the economic difficulties and the difficulties to in so far as possible. We want to guarantee our economic sustenance through our own potential and our work.

• We will form partnerships with other local and international organizations.

• We will promote courses that will teach us how to elaborate, implement and carry out income generating projects and train us to administer and manage economic resources. Honesty and Solidarity will be our flags in the income generation projects and in our social relationships.
• We propose to have constant evaluations to correct errors and continue the development of a just and solidarity economy.

• Women will be included in decision making in all activities, whether educational or income generation and administrative management. In our midst, men and women will have the same rights.

• We will help the other districts and provinces to create local associations of people who were or are affected by leprosy.

• We will make efforts to make viable the communication between the associations of people who were or are affected by leprosy and other similar organizations in Mozambique.

• We want to share and unite ourselves by heart to all the people in the world who were or are affected by leprosy by the creation of IDEA - MOZAMBIQUE. For this end, we established IDEA - MOZAMBIQUE during the workshop.

We thank all those people who, directly or indirectly, made this Workshop happen. It was very nice, we learned a lot. Thank you.

Founding members of IDEA Mozambique:

“We Felt Stronger and Also Valued Because We Are Not Alone”

“We received IDEA’s visit in March 2004. Through this visit we got to know the work that is done in other countries against the discrimination of people who are affected by leprosy.

“We felt stronger and also valued because we are not alone in this struggle.”

-- Communication sent from members of ALEMO in Mozambique to IDEA prior to the establishment of IDEA Mozambique.

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Left to right: Jaime Tomas Cabeto and Natalia Isabel da Graça Marçal, IDEA Angola; Chamada Abibo, IDEA Mozambique; and Alhaji Shehu S/Fada, IDEA Nigeria. Photo by Pamela Parlapiano