

“Our Work is One of Listening Very Closely”



Zilda Borges with Ana Niemeiskhtz de Sousa. 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, Brazil, IDEA's President for Advocacy

IDEA Center for Counseling and Capacity Building

“The number of people seeking help increased significantly this year. Although they had completed their treatment, they still carried with them the personal difficulties in trying to deal with the fear of stigmatization. People came on their own to the counseling center because the word was spread around by people who benefited from the psychological counseling or who had received a visit in their homes from IDEA. More people in the community also knew about our work.”

-- Zilda Borges, Psychologist, IDEA Center for Counseling and Capacity Building, Brazil

Psychological support and counseling are crucial to the successful treatment of people with leprosy. Despite the availability of a cure, IDEA has observed that when people are first told their diagnosis, many become severely depressed and some even contemplate suicide. Zilda Borges, a trained psychologist who has herself experienced leprosy, has established the IDEA Center for Counseling and Capacity Building in Campo Grande, Mato Grosso do Sul, to provide individual counseling to people with critical emotional needs. Here, individual counseling and general information on language, self care, self-esteem, and human rights is provided. The Center’s counseling activities, partly supported by the German Leprosy Relief Association, The Leprosy Mission New Zealand, and The Damien-Dutton Society, also includes serving as a resource for psychology students and community volunteers.

In addition to counseling people affected by leprosy, the Center also counsels people who have received information about leprosy, are still afraid, and have difficulty changing their negative attitudes towards individuals affected by this disease. During the counseling process, many people have identified the reasons for their fear and have decided to change their negative attitudes.

“People who never had the disease but who are afraid of those who have had it or have it now are much more resistant to change of attitude. Our work is one of listening very closely and talking to people. For this we develop the technique of the street group, that is, on a street in a poor neighborhood where the families are rubbish collectors for recycling. We choose a woman leader who lives on the street. She invites her friends and neighbors for a chat about human rights and prejudices that people with leprosy face. They decide on the date and time of the meeting and we go there (IDEA leaders and/or psychology students) to talk with the group. The meeting takes place inside the leader’s house or under a tree in people’s gardens. In this environment people feel more at ease to talk about their fears in relation to Hansen’s disease.

“The total number of people who were reached through street groups and school presentations in 2009 is 7,015. Of these, 1,100 were referred for counseling. Of these, 122 were people affected by leprosy themselves and 978 were relatives, neighbors and close friends of people who have or have had Hansen’s disease.”

Support and Education

“Expedito lost his sight when very young. When I went to visit him for the first time in 2005, I met Expedito in a dark room, alone. He spent his days inside his very small room built with pieces of old wood. He lived in silence and once in a while he would make a little noise with a stick on his bedroom wall, waiting for someone to do something for him. Expedito did not feel safe to walk alone or even inside his home. His situation was like some people with Hansen’s disease who remain hidden inside a room because they are afraid or ashamed.

“Expedito had never studied. When asked what he most liked to do, he said he liked music. A woman then gave Expedito a keyboard. He played music without ever having taken a lesson or attended music school. He learned by listening to the sound of music on the radio. He said: ‘I think it is a gift that God gives to someone who lives in solitude.’

“After many visits to Expedito, one day he said, ‘Now I want to go to school, but I have no shoes.’ So, I went to a store and bought a beautiful pair of shoes as a present for Expedito. The next day Expedito was going to a school for the blind. He learned to walk with a cane which gave him autonomy. He then had a great dream – to play his keyboard in the band at his church. When I visited him in 2008, he was playing his keyboard in his church.”

-- Zilda Borges



Amanda (right) is an eleven-year-old girl who coordinates a support group for children who live in the area of the city where people make a living by selling what they find in the garbage dump. *IDEA photo*

“I get children in the community together to talk about Hansen’s disease. I find children who would like to start support groups.”



Expedito Silva, seated at the keyboard. Zilda Borges is to the right, holding the baby on her lap. *Photo by Pamela Parlapiano*

Maria Graciela Baéz Benitez, Paraguay



Graciela Baéz Benitez, makes a presentation about her life experiences in India. *Photo by Henry Law*

“My name is Maria Graciela Baéz Benitez. I’m from Concepcion, Paraguay. My illness began during the year of 1993. I didn’t believe it. My mind couldn’t grasp it. Nobody in my family had leprosy . . . I was discriminated against because of the disease. Some neighbors suspected that I had leprosy . . . My mother couldn’t keep the secret and eventually told them. They were afraid and refused to let me near them because I had leprosy, saying that I could infect them. One neighbor won’t drink or eat anything that comes from my house. We would invite her to come to my house, but she would not come.

“I have other experiences perceiving when people are afraid to be near me. At the health centre in Concepcion, various people including doctors and nurses are afraid to approach people affected by leprosy. They are afraid of getting the disease. We know that one can’t get it attending people affected by leprosy. My family lived with me and never got it.

“When I went looking for a job, I left my resume in various places; they said that they would hire

me but they never called. The company doesn’t want to have an employee with scars and that is why they didn’t give me the job. I can be better than a person who doesn’t have scars, but the company will always prefer those who don’t have them. They will prefer one who has a better appearance. They don’t look at the interior of people, their character -- they look at appearance.

“But, you know, even having the information that taking the medication I wouldn’t infect other people, I was very afraid, especially for my little sister who was a baby. I asked my mother to wash my clothes separately. I was afraid of infecting her. My mother didn’t listen to me and washed all the family clothes together.

“When friends came to the house I used to hide in the bedroom. I always hid and I asked my father to put a timber fence around the house so that no one would see me in the yard . . . I was locked within myself and in my home. I lost a lot of my youth.

“My older sister didn’t find out until 2006. She had her doubts about my illness. In January, IDEA -- through Zilda and Solange -- came to visit Paraguay. I talked a lot with Zilda and she said that

it would help me if I told my sister because it would be another person to give me support. I took courage and told my sister. She said she continues to be my sister just as before.

“I began to leave the house to go for a walk, to go to church, to visit other people in a normal way only when Zilda and Solange came to my home. I always used long sleeved blouses, rarely short sleeves, because people asked about the condition of my arms and legs. They keep staring and that bothered me. After Zilda’s visit I talked a lot and saw how people manage to overcome the fear. This helped me. I have overcome the fear. Look now, I’m wearing normal clothes.

“My mother and father supported me. My mother never left me alone when I couldn’t sleep with the reactions. After my mother told him, my father told me that I would have to go back to having contact with society. He told me that I could be the same person I was before. Dynamic. I can say that I have a wonderful family, excellent.

“I want to complete my studies and help people who are affected by leprosy. I passed through many moments of embarrassment at the health centre and I don’t want people affected by leprosy to experience what I did.

“Today I feel that I have more dignity. I won’t let anyone walk on me. If a person doesn’t like it, or is afraid, or doesn’t want to be there where I am, I will leave quietly without feeling hurt or without dignity. I also feel dignified by being able to understand and respect people who are afraid of me -- without, however, permitting myself to be walked on or rejected by them.”

-- Interview by Zilda Borges and Solange Gomes da Silva; Translated from Spanish by Solange Gomes da Silva



Graciela Baéz Benitez (far right) with Tien Pei Lee, IDEA Taiwan, Ymelda Beauchamp, IDEA USA, and Zilda Borges, IDEA's President for Advocacy. *Photo by Pam Parlapiano*

Josefina Gomes Correia, Guinea Bissau

“I am Josefina Gomes Correia. I am from Guinea Bissau. I was born in Guinea Bissau. I am already part of IDEA’s team. My mother separated from my father and I lived with her and my siblings. After my mother’s death in 2001, my older brother made us, my little sister and me, leave because that house was his father’s house. We had to live in my other sister’s house. She is my mom’s fifth daughter.

“At this moment I am working as a Journalist, at ‘Agência Noticiosa de Guinea Bissau,’ and I am also studying Sociology, third year. Well, I will talk about my life.

“As you know, most of the people in Africa in particular are poor. And my mother, to provide us with an education, she had to work really hard. She used to make food such as sweets and others to sell, and we learned with her, and we helped her sell things to help with our education, buying school supplies, and paying our tuition. After middle school, my father started paying my high school. I studied in a religious high school. Besides paying high school, he also bought me school supplies. After that I did a French course in professional education. I was going to be a teacher. But then I’ve changed my mind and started studying Journalism. I am enjoying my life.

“During my journey, I had Hansen’s disease. But I thank God because since the beginning my mother noticed that I had some marks. Before that, one day at school, my friends noticed something like a scratch, a very clear mark. They asked: ‘Were you in a fight yesterday?’ And I said: ‘No, I don’t like fighting.’ And they insisted, and I said no. After that it started growing, and my mother said: ‘There is something on your face.’ I said: ‘I don’t know.’ And she was concerned because ever since I was a little girl, I got sick very easily. I am always sick, and always when I get sad for some reason she gets very concerned. I got Hansen’s disease 12 years ago. My mother was concerned and told me I had to go to the hospital. There is a specialized religious hospital in Guinea Bissau, and my mother decided that I should be admitted there. I stayed there for a month, I spent Christmas and New Year’s there, and then I continued the treatment with the medicine at home for two years . . .

“I am working as Journalist. And with my salary I pay my college. I pay my education by myself. You know, there is a lot of research in sociology. I am a very curious person. I like learning and discovering things, and sociology is part of the society, the study of society. It makes people closer to the society. It makes it easier to understand when some kind of phenomena happens, the meaning of this happening, its origins.



Josefina Gomes Correia, Journalist. *Photo Courtesy of Josefina Gomes Correia*

“Sociology and Journalism -- I think these two can work together. Being a journalist I will report things while working at the journal. I am in contact with people and I am publishing. I do my research and I publish it. If I do research related to sociology, I can work with social communication. It won't just be people reading the news, I can use my social communication to educate them. I think it will work.

“Yes, I noticed people suffering and being discriminated against. When I started working as a journalist, it was very touching for me. I wanted to inform people that Hansen's disease really exists, and they must take some precautions. I want to really raise people's awareness not to discriminate against those who have the disease. There are a lot of people thinking, for example, if I have Hansen's disease and if somebody touches me, this person will be infected (laugh) . . . and they run away from people. So I want to work in this sense, raising the awareness in people not to isolate the others, showing that Hansen's disease is curable, helping those who have Hansen's disease. This is it -- I want to work in this sense, bringing knowledge to people.”

-- Interview by Zilda Borges; Translated by Daniela Saldanha-Souza



Josefina Gomes Correia, IDEA Representative, Guinea Bissau, with women at a leprosy village in India. *Photo by Henry Law*

Nicole Holmes, U.S.A.

Each day when we awake to the sunshine in our eyes,
We are given another chance to live,
And take life one step at a time.
We are faced with the pressure of finding life's course.
We must look deep within and see what we want.
The search for self-knowledge is what must be won.
Although we may feel the need to understand,
Sometimes the only solution is when time takes our hand.
The future we can neither predict nor see.
The only solution is to live life truthfully.

-- "Journey" by Nicole Holmes



Nicole Holmes, IDEA USA Support Group Coordinator, Teacher, Future Counselor. *Photo Courtesy of Nicole Holmes*

“Too often we forget that leprosy is not only a disease that affects our physical health, but our mental health as well. It can impact our family life and our social support system. This is why it is so important to consider our mental and social well-being as a whole. In my own experience of having leprosy, I was best able to cope with my illness and to make a fully recovery when my stress levels were lowered, and my family and friends had come to understand my disease and my needs. I realized how important having these things were to me, and strived to be able to offer the same support to individual and their families dealing with the diagnosis of leprosy (<http://www.hansensdisease.com>). It is now my goal to open up my own counseling center focused on helping those struggling with the effects of having a chronic illness. I believe my own experience will offer a great perspective on how it is possible to find strength and courage to overcome any obstacle.”

-- Nicole Holmes, IDEA USA Support Group Coordinator

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

Addresses for Correspondence

Dr. P.K. Gopal
President, International Relations
58 Selvam Nagar, Collectorate P.O.
Erode 638 -011 INDIA
Phone: 91-424-226-7395
FAX: 91-424-226-0729
E-mail: ideaind@sancharnet.in

Ms. Mary O'Friel
Administrative Coordinator
699 Main Street
Ashby, MA 01431-2309 USA
Phone: 1-978-386-0048
FAX: 1-978-386-0065
E-mail: ideaofriel@verizon.net

Ms. Anwei Skinsnes Law
International Coordinator
32 Fall St., Suite A; P.O. Box 651
Seneca Falls, NY 13148 USA
Phone: 1-315-568-5838
FAX: 1-315-568-5891
E-mail: alaw@idealeprosydignity.org