"This empowerment of trust and acceptance and also the sharing done from the depth of our hearts made us at ease. We were terribly delighted to the core. We felt with the words, 'I'll Go With You' that our dignity and pride were restored. All faces were radiant with joy . . . . Now I too feel very free."

Mrs. Nevis Mary, IDEA India, following the First National Empowerment Workshop for Women Affected by Leprosy in India

"When I go back to the people I am representing what will I tell them is the most important thing I learned? I know that I have a future. I know that I can do so many things."

Patrick Orji, workshop participant from Abia State, speaking at IDEA's Workshop in Nigeria

Unless noted otherwise, newsletter photographs are by Pamela Parlapiano
IDEA's First National Empowerment Workshop for Women in India

I am Nevis Mary, 45, affected by leprosy. When I was invited to participate in the Workshop on Empowerment of Women Affected by Leprosy, an inner force grown out of the years of hurt and pain propelled me to attend the workshop at Chennai, 500 km away from my place. Of course my mind was wavering and fluttering, not only with the recollections of the past but more so with what was going to happen that could affect and hurt me due to my participation in the workshop.

Participants from various States of India as Andhra Pradesh, Bihar, Maharashtra, Tajasthan, Tamilnadu and also from our neighboring country Nepal, numbering 40, participated in the Workshop. Though different languages like English, Hindi, Narati, Nepali, Tamil and Talugu were spoken, we were all united, as one laughter echoed all over the Hall. Love and affection sprang from the depth of everyone's heart. The sharing and caring generated happiness beyond one's imagination.

Each one had her own story grown over the years of suffering, humiliations, beatings and mental agony. For many, this was the first stage -- to talk -- yet boldly they expressed their feelings which were hidden deep within their hearts. Such an outlet gave us immense joy. It was as if a heavy burden had been lifted off.

The climax, I think, was on 23rd September, 2003, when we had group discussions. All the Tamil speaking participants grouped on one side and on the other side Hindi speaking. It excited us the most emotionally. We began sharing, frankly without hesitation, our pains, strains and joy, the fear and agony of being teased, hurt and rejected.
The Courage to Face the Challenge

"After being invited to participate in IDEA's International Women's Conference in New York, I decided to tell my daughters about the disease." -- Mrs. S. Valamarthy, who participated in the Women's Workshop in India together with her daughters and husband.

Mrs. Suseela supports herself and her mother by weaving table mats. A participant in the Women's Workshop, Mrs. Suseela was divorced by her husband due to leprosy.

The main issues discussed were: What can't we do because we are affected by leprosy? What can't we do because we are women?

In spite of many messages like, "Leprosy is not infectious; Leprosy is curable; Free treatment is available; Leprosy is not hereditary," the affected persons, even if they are in the beginning stage just having patches and no disability, are very much afraid of going to a doctor for treatment. Even if they are given treatment, they start developing a loneliness in their hearts.

Some participants from the small villages (where only leprosy affected people live) said that they are happy without any problem within their villages. But once they go out, they face the same discrimination everywhere. Even family members show hatred when they come to know about the disease.

Economic hardship is another main problem. Some were in need of financial assistance for house building and for their children's education.

People like Nevis Mary, Devi, Valamarthy, felt that there is a rigidity in their minds due to the burden of secrecy and that creates other diseases.

At last, we all came to a conclusion that we, as women affected by leprosy, should not give up our dignity in any aspect. Rather, we should support and encourage one another so as to lead a happy and normal life.

Then came the time to say good-bye as the meeting came to an end. Our hearts almost broke and our eyes were full of tears when we bid farewell to one another. But each one had the courage to face the challenges, to strive and to succeed. I was eager to meet mine

Mrs. Nevis Mary, IDEA India
"We thought it was going to be like others we have attended. Little did we know it would be as marvelous as this."

Mohammed Ahmed, workshop participant from Kebbi State

"I want to become self-reliant; I do not want to beg."

Ibrahim Bakanike, workshop participant from Sokoto State

"In the North there is a place where I came from, if you want to go out with the healthy people they will not allow you. If you want to buy something, they will not sell to you because you have leprosy. If you want to drink water, they will not sell to you. If you want a wife, they will not allow you to marry her. We have taken our treatment and have been declared cured but there is still stigma."

Abubaker Musa, workshop participant from Plateau State

"I am industrious -- I can bake; I can knit."

Ekakette Isaiah, age 19, workshop participant from Akwa Ibom State

"I stay in one place and work as secretary of Katsina State Association of People Affected by Leprosy . . . I advise fellow members of the association that begging is not good. They contribute money to the association every week; from that money they help those in need of welfare who cannot work. I have said goodbye to begging."

Aminu Usman, workshop participant from Katsina State

"Reverend Musa said that, even though he is affected by leprosy himself, he has always feared the disease but, since joining IDEA, he no longer fears leprosy."
Minna Declaration

We, the participants in the first "IDEA Nigeria Empowerment Workshop" held 2, 3, and 4 December 2003, in Minna, Niger State, Nigeria declare:

• That opportunities for exchange such as this IDEA Nigeria Empowerment Workshop be increased to provide people with an opportunity to promote a network of support; build self-confidence, share views, ideas, and experiences, and discuss; eliminate the cycle of poverty and social isolation; identify and follow-up on activities to improve their lives;

• That all individuals, including persons affected by leprosy, are accorded their full rights and privileges consistent with the Universal Declaration of Human Rights and that their human rights and dignity be restored;

• That people affected by leprosy acknowledge their rights and responsibilities as members of society, and remain and become actively involved in their community;

• That persons challenged by leprosy recognize that they have a vital role in eliminating prejudice and discrimination associated with this disease;

• That individuals affected by leprosy build solidarity with those who share similar social or physical challenges, to expand opportunities for full and equal participation in society for all;

• That international government and non-government agencies promote the full integration of persons affected by leprosy in their community, and do not depict people through words or in photographs in ways that compromise their dignity;

• That people challenged by leprosy build solidarity with each other to support the improvement of their daily lives, as well as to address the global issues of stigma, discrimination, and human rights violations;

• That persons affected by leprosy work with each other and in partnership with government and non-governmental agencies to improve their social, physical, economic, and psychological situation;

• That organizations involved in leprosy and in human rights involve people affected by leprosy as teachers, spokespersons, and lobbyists;

• That discriminatory terms and acronyms that define people by their disease no longer be used;

• That society is made aware of the modern realities of the disease to reduce stigma and discrimination and to ensure that people never have to be separated from their families and community;

• That the history of leprosy and the experiences of those affected by it in every country be remembered and exchanged to foster a worldwide understanding of the issues surrounding this disease; and

• That the final victory in the fight against leprosy only be declared when there are no more persons to be cured, no more disabilities to be treated, no more discrimination to overcome, and when persons once affected by this disease lead full, rewarding lives with the same opportunities, rights, and responsibilities as their fellow citizens.
Mr. Prakasam, IDEA India

I am Prakasam, born at Rampakkam, Villupuram Taluk, India. I was the only son to my parents. My mother died when I was five years old. Immediately after my mother died, my father was affected with typhoid and also afflicted with leprosy.

When I was a small boy I too got the signs of leprosy. Patches appeared on my body. Since we were not able to read or write, we did not know much about it. The villagers came to know about the disease and my father and myself were sent out of the village to seek medical help in several different leprosy hospitals. After more than ten years, we were discharged as cured and returned home.

Since our family did not take care of us, we divided our property and sold our land. We again came to Chingelput and finally settled there. We were selling aluminum vessels. The income from the business was not enough to pay our rent or electricity, or to buy food. We started selling rice. Since the money was not enough, we finally landed in debt.

In those days, there was an acute scarcity of rice all over India and I started smuggling rice from Chennai to Bombay. We rode the trains as a group without buying tickets, but were not arrested since we had leprosy. During that time my father passed away. I loved a girl name Lakshmi and got married. We had a girl named Rajeswari. When my daughter was five years old, she was also affected by leprosy and was admitted in the leprosy hospital at Kumbakonam. My wife passed away due to sickness when Rajeswari was 11 years old. I kept my daughter with my friends' family so that they could raise her.

I was a beggar in Delhi but then returned to Chennai where I sold iron scraps collected from nearby industries. At the same time I continued to smuggle rice and, like many residents of the leprosy village, also sold opium. Although this was against the law, the police would not touch us since we had leprosy. One day, a high police officer came and explained to us how drugs spoil the lives of young people and society in general. I made the decision that we should stop selling opium and all of the opium from different houses was collected and burned right in the village itself. That was the end of our illegal activities.

For the past 20 years I have worked as the President of the Tamil Nadu Leprosy Patients' Rehabilitation Guild, trying to restore dignity to the lives of the residents of the leprosy villages. Many have taken up respectable businesses. We are working together with different organizations to educate our children. I am married again.

I recently received an Award from the Tamil Nadu Government for social services rendered to persons affected by leprosy. Now my son has gotten married and has a son. He is the breadwinner of my family. Still, I am working for the betterment of living conditions of persons affected by leprosy. I hope I will continue this as long as I live.
When I was 17, I moved to Ankaful camp, as it was then called. It was a place where many people who had been cured of leprosy lived -- those who did not want to return to their hometowns. I was being fed from the community kitchen but learning to live independently. While it was very hard for me, I did succeed and I even began my secondary education. The problem was that many students did not want to play with me. I was an ex-leprosy patient and I had disabilities. There was even a teacher who refused to mark my work. Thank God for two boys, James and Joseph, who did play with me. They made my life bearable. All this gave me a determination to help people with disabilities because when people reject you, life does not seem worth living.

I passed my secondary school examinations in 1993 when I was 22, but it would have been very difficult for me to continue my education because this would almost inevitably require me to be a boarder. With my disabilities, being a day student was difficult enough; boarding students would not have accepted me.

I then started to help one or two children at Ahotokurom who had special needs. Sister Pat then decided to set up a special educational needs unit and I began teaching there in 1995 when I was 24.

I met Lucy when she came from her hometown to have some treatment at the leprosy hospital. She understood my situation and, despite a great deal of discrimination and criticism from others, Lucy was strong in her commitment. She dismissed them all and we were married in April, 1994. So by God's grace I was and still am a teacher at Ahotokurom and I am married with three children, two boys and a girl - Patrick, Nyarko and Mary.

In the year 2001, when Father Doug was visiting Ahotokurom he brought an invitation for me to visit England and spend some time in the parish primary school. I was shocked and couldn't imagine how such an expense could be met, but when Sister Pat began preparing my official application, I began to take it seriously. It so happened that when I was waiting for my passport to be made available at the passport office, I met the very same teacher who'd previously refused to mark my schoolwork. He was working there now. He sneered: "What are you doing here?" I told him that I was awaiting a passport so that I could travel to England. He'd been trying to travel for many years and was shocked and couldn't believe that someone whom he'd looked down upon so much should have such a privilege.

It is yet another example of how my life has been transformed -- changed for the better, from a deprived childhood of suffering to the present day where I have a wife, a family, a home, a job and a wonderful trip to England. Ghana's national symbols are "Gye Nyame." It means "Only God" and that is what is behind the changes in my life -- "only God".
Efua Grace - Going Home

Efua Grace, IDEA Ghana

Efua Grace was sent to the hospital when she was eight years old due to leprosy. Although she was cured within a year, she remained in the hospital. Plans are now in place for Efua Grace, who is 19, to return to her home town. According to Kofi Nyarko, the Chairperson of IDEA Ghana; ". . . we can say that the teachings of IDEA are really working now in Ghana."

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