



Newsletter from the Sierra Madre #28 March 1993



Project PROJIMO: a program run for and by disabled young persons in western Mexico

Project Piaxtla: a villager-run health care network in the mountains of western Mexico

The Hesperian Foundation: a small group committed to health rights and informed self-care

In this issue of our Newsletter, we take a look at different rehabilitation projects. Our articles deal with different particulars, but we feel that together they paint a broad picture of the types of initiatives that make for truly successful rehabilitation programs, while pointing out some of the common mistakes that doom other projects to failure.

We would appreciate hearing your reactions to these articles and learning about your own experiences in this field.

Disabled Children in the Slums of Nairobi

David Werner

The two faces of Nairobi

The 17th World Congress of *Rehabilitation International* was held in Nairobi, Kenya in September, 1992. Nearly 2,000 participants from more than 80 countries attended. For most, Nairobi was just another modern city: giant hotels, spacious parks, thriving tourism, too much traffic, and a reassuring blanket of smog. The wild animal park on the edge of the metropolis has all the charm and adventure of the "drive through" portion of the San Diego Zoo.

The first page of the slick program guide for the RI Congress, under "Venue," tells us:

Nairobi, Kenya's Capital with a population of about a million, is a bustling cosmopolitan City, the home

of the United Nations Environmental Programme (UNDP) and the United Nations Human Settlement Program (HABITAT). It is also the headquarters of many multinational Companies operating in East and Central Africa.

The showpiece of the city is the KENYATTA INTERNATIONAL CONFERENCE CENTER, venue of the [RI Congress]. The 32 story complex which dominates the Nairobi skyline offers 26,000 square feet of unobstructed floor area in its Plenary Hall and a host of other Conference and meeting rooms...

There is a choice of hundreds of tours to be taken from Nairobi itself. Four hours in the Nairobi

National Park, just 10 minutes from the City Centre, will insure a satisfactory photographic safari.

However, this opening eulogy ends with sobering words about pick-pockets who "prey on the careless pedestrian" and warns that ". . . it is advisable to stick to the area marked on the map in green."

Although officially Nairobi's population is put at one million, unofficially it is said to have more than two million inhabitants. However, an estimated 60% of the population live in squatter settlements and sprawling shanty towns, without even the most basic public services. Except for sporadic occasions when the city's urban renewal program bulldozes down a few thousand shacks leaving the inhabitants homeless, the usual official response to Nairobi's "septic fringe" is to pretend it does not exist.

At the RI Congress, this "forgotten city" within the city, with its myriad of disabled people, was similarly overlooked. There were numerous lectures on the situation in Kenya and on community programs to *reach the unreached*. But there was no mention (at least in the sessions I attended) about the destitute dwellers of Nairobi's shanty towns. The only indication that many persons with disabilities

were quietly excluded was the large number of disabled beggars on the sky-scraper studded streets surrounding the conference center.

Squatter community based rehabilitation: Mathare Valley

I, like the other participants in the \$5 million World Congress, would have remained ignorant of the *other face* of Nairobi, and the desperate state of its peoples, had it not been for fortuitous links to a remarkable woman who has started a small, independent rehabilitation



An estimated 400,000 people live in the squatter district of Mathare Valley.

and development program in one of the largest and poorest shanty towns.

Her name is Mwema Nkosi (a pseudonym). The initiative she has organized over the last seven years comes closer to real *community based rehabilitation* (CBR) than many other programs that go by that name. However, Mwema did not attend the RI Congress in her own city because she could not

afford it. I learned of her through a Canadian, Laura Krefting, now working as a CBR trainer in Indonesia. Laura had been given Mwema's name by friends in Canada who help support her program. While in Nairobi for the RI Congress, Laura had given Mwema a copy of *Disabled Village Children*, and Mwema had invited Laura and me to visit her work with the families of disabled children in the Nairobi squatter settlements.

Mwema Nkosi has training as a psychological counselor. On completing her training she accepted a government position, but soon became concerned that the needs of the most deprived sector of the urban population were completely unaddressed. She began working with women in the shanty towns, as a volunteer two days a week. A year and a half ago, thanks to very modest contributions collected mostly by her Canadian friends, she began working full time in the "project."

Mwema took us to visit the largest settlement she works in, called Mathare Valley, which has about 400,000 inhabitants crammed into tiny wattle, tin, and cardboard shacks in a hilly area that looks to be less than one square mile. (Mathare Valley is reportedly the second biggest squatter settlement in the world, exceeded only by an enormous settlement in Bombay, India.)

The Mathare Valley squatter settlement, she explained, dates back to colonial days. Well-to-do whites in the city brought large numbers of poor girls from the countryside to work for "slave wages" as house servants and baby sitters. The whites also brought young men from the rural areas for menial labor. Neither the girls nor men were able to bring their families. Separated from their wives, many of the men had passing relationships with the young house servants.

On becoming pregnant, the girls were fired from their jobs. Unable to return to their rural families, the only way to survive was to sell their bodies. Rejected and exploited, many moved into makeshift shacks on the edge of the city. They subsisted through prostitution and peddling of a potent home brewed liquor called *chan'ga*...

occupations that remain for them a main source of income to this day.

Freedom from colonial rule brought no liberation to these outcast women. Today 90% of the shacks in Mathare Valley are occupied by single mothers. Living conditions are appalling. Mothers with six to eight children reside in tiny, dirt-floored shacks, no bigger than an average bathroom. The tin roofs leak and the floors turn to mud when it rains (it was drizzling when we visited). The shacks are jammed next to each other, filling every

available space. There are no latrines and *no space to build any*. Open, foul smelling sewage ditches flow by the edges of the huts.

Although the tenants of these settlements are squatting illegally on government land, they pay rent to wealthy "slum lords." The slum lords initially paid a bribe to corrupt government officials for permission to put up a series of shacks, which they then rented to



Open sewage ditches run down the narrow paths in Mathare Valley.

the poor. The more shacks that can be crowded into a small space, the more rent the slum lords can collect. Since officially the shacks do not exist, the slum lords pay no taxes and are subject to no standards, inspections, or controls. And the inhabitants receive no public services—except sometimes when an epidemic breaks out that might spread to more affluent neighborhoods.

Children in the Mathare Valley are everywhere, undernourished but astoundingly full of life. A lot of teenagers and men seem to be

just hanging about. Mwema explained that some of these men live with the women, but usually on an intermittent basis, often abandoning them in times of crisis.

Mwema estimated that only 5% of the adult population in the squatter settlement is legally employed at any one time. Nearly everyone subsists through the informal economy—a better option than paid employment, given that wages for unskilled labor are very low. Wages are about 1200 Kenya schillings a month (about US\$40.00). Of this, 300 KSh are taken out in taxes. The slum lords charge the residents up to 500 Ksh a month. The city authorities extort a "security fee" of 50 Ksh and, if not paid, will confiscate the family's fire box (used for cooking). To travel to and

from their place of employment, bus fare is usually at least 20Ksh per day. Add it all together and there is nothing left for food. So most people simply cannot afford to be employed in the formal sector.

With the high unemployment rate and the overall hopelessness of the situation, drunkenness is high, especially among the men. There is also a lot of drug use, mainly glue sniffing and bangi (marijuana), with a still limited but increasing use—and trafficking—of cocaine.

With the high rates of alcoholism, unemployment, and hopelessness, the rates of violence, crime, and rape are also high. Mwema explained that one reason why virtually no public services reach Mathare Valley is that government workers—except for armed policemen—dare not enter. Strangers to the area are often beaten and robbed.

Abuse by the police is another common problem. Almost at random, police accuse women of buying or selling home brewed *chan'ga*, in order to extort money out of them. The woman who refuses to pay is thrown in jail. And once in jail many detainees "get lost." Years may pass before they go to trial or are released.

Mwema is convinced that the reason the police department so brutally harasses the women for production and sales of home brewed *chan'ga* is that the national and multinational alcohol industries have such a powerful political lobby. It is an attempt to reduce a very major form of competition—through terrorization.

Even the dismal living quarters of people in Mathare Valley are tenuous. When a mother leaves her small hut in the morning, she is never certain that it will be there when she returns. Sometimes the government or a building contractor sends in bulldozers to "clean up" a portion of the slum for an industrial project. But more often they simply pay thugs to set a fire. The cardboard shacks go up like tinder. During my stay in Nairobi,

300 huts went up in flame one day and several people burned to death.

AIDS, which is such an enormous problem in most of Africa today, has an especially high incidence in these communities. Prevention campaigns had reached the slum, as we could see by the number of used condoms on the muddy pathways. But in an area without latrines or sewage disposal, this preventive health measure has in some ways backfired. With no other toys, children use the discarded condoms as balloons, and sometimes contract diseases. Mwema sees the lack of safe disposal of condoms as a growing health problem.

Hungry adolescents have found a way to profiteer from people's fear of AIDS. Filling discarded syringes with blood taken (they say) from persons with "slim disease," they corner strangers and threaten to inject them with AIDS infected blood if the person does not hand over all their money and goods. Apparently this form of extortion has become quite common.

At most, only 20% of the children in Mathare Valley go to school. Now that schooling is no longer free and shoes are required for attendance, many mothers cannot afford to send their children.

Children disabled by poverty

From the time she began to work in Mathare Valley, Mwema has been concerned about the large

number of disabled children. Such children live in dreadful circumstances. Their original disability is often complicated by malnutrition, infectious disease, and neglect. Their mothers, struggling to keep their families fed and alive, understandably give the little food available to their more able children who can bring in some income, mostly through stealing. (The shanty town is too far from the urban center to send children out to beg.)

Many mothers face a difficult decision. Do they lock up their disabled child in the hut all day, in order to go out and try to earn enough money to feed her? Or do they stay home with their disabled child, and let her starve? Under such circumstances, Mwema soon realized that rehabilitation work with disabled children must focus on helping the single mothers earn a bit of income, if possible, out of their own homes. With the help of very limited outside funding, she helped mothers of disabled children to set up small income generating initiatives. Some mothers sell *paraffin* (kerosene), others charcoal or firewood. She also brought several mothers of disabled children together to take turns caring for a small group of the children, so the others could go out to earn money.

To explore possibilities for other solutions, Mwema began to meet with various groups of the women. Women's committees were formed and subsequently a number of cooperative work

groups were established. Several foot treadle sewing machines were obtained, and sewing cooperatives have been set up. Currently there are six women's groups with an average membership of 20 to 30. Some groups have begun small chicken-raising cooperatives. Others run a nine-month course in tailoring and dressmaking (where half the class pay fees that cover the costs of those who cannot pay). Some of the Masai tribal women, who have migrated to the city and located in the settlement, have begun to produce some of their traditional crafts, and marketing channels are being set up for tourist trade and export.

Perhaps the biggest breakthrough of all is that one group of women has managed to buy land and, with their own manual labor, has built a house in an open area across from the Valley, in a much healthier environment. Thus the slum dwellers are learning that through united action they can begin to change the conditions which for so long have seemed insurmountable.

At present, the program consists of a staff of nine persons, most of them exceptional women from the shanty town itself. One of the most capable is Hadija (a pseudonym), who is learning, among many other activities, basic physiotherapy from a therapist who the government now sends out for one afternoon a week. The program has also succeeded in work-

ing out arrangements for free medical treatment and orthopedic surgery with doctors in a private mission hospital. Mwema explained that it was very hard to gain admittance to the public hospitals or to get competent treatment there.

For some of the multiple disabled children living in the worst circumstances, Mwema and her team felt that institutional care might be the only answer. She made arrangements for several of the children to be taken to a



Mothers and grandmothers work together to build a cooperative bakery.

Mother Teresa Home on the outskirts of the city. On taking the children there, she was disturbed to learn that, prior to admittance, a paper had to be signed agreeing that if the children died their bodies could not be reclaimed. Only later did she learn that this was a prophecy of death. In the Home the children were severely neglected, in spite of substantial international funding. The children began to develop pressure sores and infections from lying unattended in one position, for long periods of time. Two of the children died.

I asked Mwema how children were treated in the large government homes for abandoned and orphaned children. She shook her head emphatically and said, "Much worse!"

Mwema tried to get some of the disabled children into school. Government officials suggested she take them to KISE (Kenya Institute of Special Education) which has a large center a mile or so from Mathare Valley. But for the mothers to get their children to the school is virtually impossible. Most of the settlement is completely inaccessible to any kind of transport. The children would need to be carried on steep muddy paths for long distances.

In time, the women's committees decided to set up a small rehabilitation center and school of their own. With help from Mwema's support group in Canada, a parcel of land was purchased from the large, unpopulated land holdings just outside the crowded settlement area. On it the community constructed a modest building known as the Maji Mazuri Center. It is staffed mostly by local community persons who are learning skills in physiotherapy and special education. At present 17 children, all from extremely difficult home situations, reside at the center. Their families are encouraged to take part in center functions and are taught skills to better meet their child's needs. When possible, they take their child home on weekends.

To help the mothers of the disabled children learn from each other, weekend “camps” are organized (often in a scout camp outside the city) where the families join in common activities, discuss one another's problems and needs, and are involved in mutual *peer counseling*.

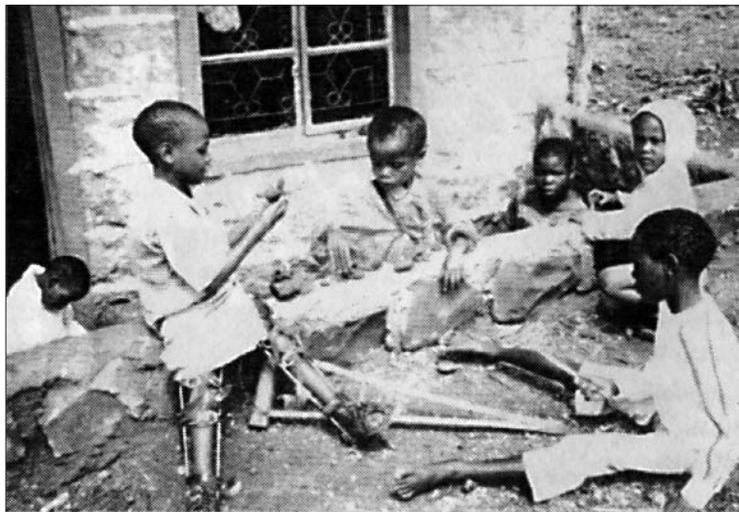
One of the most exciting activities in the community has been the development of drama groups involving the community's young adults. Themes are chosen to raise awareness both among the actors and the audience about such concerns as alcoholism, drug abuse, AIDS, and violence. By drawing from the group's actual experience, the skits explore how the frustrations of unemployment, low wages, abuse by the police, government neglect and corruption, and other factors lead to misdirected anger and destructive acts. They explore more constructive alternatives. Some of these dramas were so well done that they were performed in Nairobi's All Saints Cathedral, where they were enthusiastically received.

The first two children we visited in the Mathare Valley had epileptic seizures. The first, a 13-year-old girl who is also mentally retarded, was raped when her mother left her alone in the hut, and now has a baby the same age as her mother's youngest. In such

circumstances, Mwema and Hadija have tried to organize 'neighborhood watch' support groups of women to help protect defenseless girls.

High incidence of epilepsy

The second child had been a great worry to her mother. Because of the child's frequent fits, the mother felt she had to stay close by, and was unable to go further afield to earn a living. As a result, the family has often gone hungry. However, if the child's fits could be controlled with medication, her mother could be freed to be more productive and this would help combat the family's chronic undernutrition.



Children at the Maji Mazuri Centre.

Of the 52 disabled children whose families are now integrated into the program, 18 have fits. This unusually high rate of epilepsy is no doubt related to poor nutrition, stress, and illness of the mothers during pregnancy, with a high rate of complications and premature birth. Cerebral malaria is also a major cause.

The program has arranged for these epileptic children to get medical assessment, and medicines are routinely prescribed. However, most of the children usually go without medication because their mothers cannot afford it. Often the doctors prescribe very costly medicines, although in most cases phenobarbital—which in large quantities is very cheap—works as well. One of the possibilities we (friends of Mwema) are exploring is how to get a large supply of generic barbitol to the program, so that the children who need it can receive uninterrupted medication.

We asked Mwema if there are other programs helping to meet the needs of disabled persons in Mathare Valley or equally destitute shanty towns. She explained that in Nairobi there are several other slums where conditions, while bad, are not as overwhelming as those in Mathare Valley. These somewhat “better off slums,” she said, are those that receive more help. Health and development projects run by

large non governmental organizations (NGOs) usually work fairly closely with or follow the directives of the Kenyan government. The government—perhaps in part to save face—does not send them to the most marginalized and dangerous communities. And so, as happens in so many countries, those in greatest need fall between the cracks.

Mwema recognizes that her efforts in Mathare Valley are an uphill battle. For a small number of women and children, her program makes a great difference. She says that what keeps her going is the changes she sees in individual women; sometimes little things such as the way they begin to stand straighter, or find the courage to speak out in meetings. But Mwema realizes that dealing with the root problem of disability really means working toward social change. Poverty that causes malnutrition results in premature, high risk children, no money for immunization, and no medicine to combat malaria and high fevers that lead to disability.

In Kenya today, the squatter settlements continue to grow as large agribusiness concentrates land ownership into fewer hands, forcing more and more peasants off the land. Poverty, hunger, and social disintegration are increasing, as is the wealth and control over the economy by foreign multinationals and the ruling elite.

For every disabled child whose needs are partially met, several more appear who as yet receive no assistance at all.

Rehabilitation efforts at the community level are important. But, in the long run, perhaps the biggest contribution of grassroots programs, like the one Mwema has initiated, lies in the empowerment of marginalized peoples. As people organize to meet their own needs, they may begin to join with others to form part of a unit-

ed popular front demanding more direct participation in society, as well as greater accountability of the forces that govern it. In Kenya, such a movement is already on the rise.

A less successful program in another Nairobi slum

Two weeks after visiting Mwema's project in Mathare Valley, I had a chance to visit the health and development program run by a large Northern NGO in a neighboring slum called Korogocho. This was clearly one of the somewhat "better off" squatter settlements of which Mwema had spoken. While conditions there were bad, the shacks were larger and the whole community was a bit less crowded. It was also more accessible. The government had put in a grid of wide dirt roadways by bulldozing down thousands of shacks.

In Korogocho, the city had also put in piped water in response to a cholera epidemic which it feared might spread beyond the slum's limits. But the slumlords at once assumed control of all the water outlets, and put selected families in charge of them. So now people are charged 5 shillings for each can of water.

The Korogocho program is a classic example of how health and development interventions introduced from the outside can go wrong. The program planners quite rightly have given priority to prevention of diarrheal disease, which is the biggest killer of chil-

dren in the slum. With government approval, the NGO introduced a series of giant public latrines, each larger and more solid than even the best of the people's shacks. The latrines, which were built with government approval, were designed to be automatically flushed by a timed discharge of water every few minutes. However, three years have gone by and still the government has not got around to authorizing the hookup of the water supply. So the defecation palaces are standing idle.

The other major initiative of the Northern NGO in Korogocho appeared more promising. Since the vast slum community had no schools, the NGO worked out an agreement with the government to build some. Tracts of shacks were bulldozed down accordingly and the schools were built. However, as a result of the *structural adjustment* policies of the World Bank, the budget for public education has been drastically reduced, and schooling is no longer free. Families have to pay for schoolbooks, desks, and uniforms, on top of a "building fee." Consequently, many simply cannot afford to send their children to school.

The one very positive contribution which the Northern NGO has made in Korogocho is road improvement. In the rainy season, the wide roadways the government had bulldozed through the settlement turned into an almost impassable sea of mud. The NGO has paid to have truckloads of gravel and sand hauled in to raise

and solidify the surface of the road. This has made the road much more functional in the rainy season, and in case of medical emergencies.

All in all, however, as I compare the high-cost outside interventions of this Northern NGO with the very low cost community activities facilitated by a local Kenyan woman in Mathare Valley, I cannot help thinking that ultimately the most appropriate and far reaching solutions lie in the people themselves.

Will the multi-party system in Kenya bring more or less democracy?

Like many of its neighbors, Kenya has a history of tyrannical rule both during colonialism and since. Following emancipation from British rule, an indigenous elite, backed by brutal "security forces," firmly entrenched itself in power. As in so many Third World countries, the rulers often put the interests of foreign multinationals before those of their own people, keeping wages miserably low and crushing attempts to organize labor. In return, these "market friendly" governments received generous amounts of aid from Northern governments and development banks. Enormous wealth accumulated in a few hands while natural resources, the environment, and the vast majority of citizens were cruelly exploited and impoverished. As growing poverty and hunger bred social unrest, security measures became more repressive. By the early 90s, no one dared criticize the government openly, and any

two or three people talking together ran the risk of being arrested for holding an illegal public meeting.

In the last year or so, Kenya has been going through a series of upheavals. In December 1991, yielding to domestic and international pressures, the president dictator Daniel Arap Moi finally agreed to move toward an election based multi-party system.

Ironically, the move toward 'democratization' brought with it



increased violations of human rights, a clamp down on the press, and the arrest of political dissidents. While in Nairobi, I watched President Moi on television announcing to the military that the introduction of the multi party system requires a tightening of security measures to prevent "the disintegration of social order." To buttress social control, the Moi government has hurriedly enacted amendments to the Public Security Act, Public Order Act, Chief's Authority Act, and the "defamation and libel law." According to social activists, these new measures are "inhibiting the transition to political pluralism."

Concerned Kenyans explained to me that the recent outbreaks of violence between different ethnic groups have been kindled to a large extent by the ruling Kanu Party government. (They can be compared to the South African government's "divide and conquer" tactic of inciting inter-tribal violence.)

But in spite of General Moi's attempt to keep a lid on the growing unrest, a groundswell of organized protest is underway. Various activist organizations, including the Release Political Prisoners pressure group, the Democratic Movement, the Students Organization of the University of Nairobi, and Mothers of Political Prisoners have organized mass demonstrations and demanded audiences with public officials, calling for structural change and the release of political prisoners. Riot police have been called out to break up the demonstrations, but more and more grassroots protests are taking place. Even the swelling ranks of street children in Nairobi have begun to organize and demand their rights.

In the last few months, thanks to increasing pressure from grassroots groups within the country and international sanctions from without, there has been a gradual political opening in Kenya. The press has become more outspoken. And people speak quite openly of the corruption of the government and its failure to respond to their needs. On September 17, I read in the East African independent newspaper, *The Standard*, that a new human rights pressure group has been

formed, called the Kenya Human Rights Commission. This new group has called on Attorney General Amos Wako to repeal the new “draconian pieces of legislation which impede a smooth transition to multi-party democracy.” According to *The Standard*:

The [human rights] group noted that Kenya's current political crisis does not merely stem from the personality of President Daniel Arap Moi *per se*, but is the product of a power structure heavily skewed in favor of the executive and against the people.

The [Kenya Human Rights Commission] criticized both the Government and the opposition for ignoring the need to restructure the organs of state in order to improve the human rights situation in the country. The unfolding political situation in Kenya is remarkable in its subordination of fundamental human rights principles. All parties engaged in the political arena—whether in Government or opposition—have tended to ignore the need to restructure the organs of state in order to improve the situation of human rights in Kenya. (Sept. 18, 1992. Page 3, "Another human rights pressure team formed" by Othelo Grudush)

Kenyans welcome the multi-party system, but have little faith—even if one of the opposition parties wins the elections—that the government will become much more responsive or accountable to the people. One community health worker put it bluntly: "Whatever party wins, essentially

it will be the same big fish running the show."

Selling children for water and food

As throughout much of the world, the most basic human right is being denied to an increasing number of people in Kenya: *the right to the bare minimum of water and food needed in order to sustain life.*

Although the living situation of the people in Mathare Valley is desperate, there are other peoples in Kenya whose survival is even more precarious. One such group is the Turkana tribe near the Sudan border. Living in conditions of extreme drought and poverty, thirsty and starving families are bartering their children for water and food. They sell some to keep the others alive.

The plight of the Turkana tribe—which is now on the verge of extinction—is reportedly another outcome of the *draconian security measures* instituted in the advent of multi-party democracy. According to a statement by a former District Officer of the area, the famine stricken Turkana people receive none of the food aid which is transported through their territory to Sudanese refugees at Kakuma. The only assistance that reached the Turkanas was through a group of Catholic missionaries, “who helped to feed them while working on long-term plans to make the community self reliant.” They brought in drilling equipment to put in boreholes to irrigate the potentially highly productive

land. This “could have transformed the whole area into a food granary and rehabilitated the Turkanas.” However, the Catholic missionaries were abruptly deported and the drilling equipment withdrawn, “following cooked up charges that the missionaries were involved in arms shipments.”

According to this District Officer, “No amount of relief food would help the Turkanas out of their natural predicament. . .The best the government can do to rescue the Turkana community is to reinstate the Catholic missionaries” and allow them to proceed with the water project. (“Human auction: Police keep vigil,” *The Standard*, Sept. 18, 1992, page 2)

On leaving Kenya, I took with me diverse impressions of primary health care and community based rehabilitation. Much good work is being done. But looking at the overall situation, it is apparent that these initiatives cannot turn the tide of increasing disability and poor health. Nor can great hopes be placed on the emerging multi-party system with its facade of democracy. If real transformation toward a healthier society is to come, I believe it will be achieved through the growing groundswell of protest and popular resistance. Ultimately, the health of a people depends not on top down decrees, but on an organized demand for equal opportunity and social justice. The struggle for health is the struggle for basic human rights. ■

New Legs for Nomads Notes: A Visit to Cambodia

John Fago

John Fago is the founder of "New Legs for Nomads," an independent project under the Hesperian umbrella, which promotes advanced techniques and the development of appropriate technology in the practice of prosthetics in developing countries. He visits Ajoya at least once a year to make legs, share prosthetic skills, and explore new appropriate technologies for the construction of artificial legs. In addition, John is a photographer who is also active in socially progressive, environmentally activist, children's theater.

For an article by John on the current status of the disability movement in Cuba, please see the previous issue of this Newsletter.

More than one recent traveler to Cambodia has described it as a kind of 'twilight zone.' It is a place where everyone you meet over the age of twelve has known great tragedy.

A former colony of France (excellent baguettes are still available), Cambodia experienced relative prosperity upon gaining its full independence in 1953. As recently as 1970, 90% of the country's farmers owned their own land.

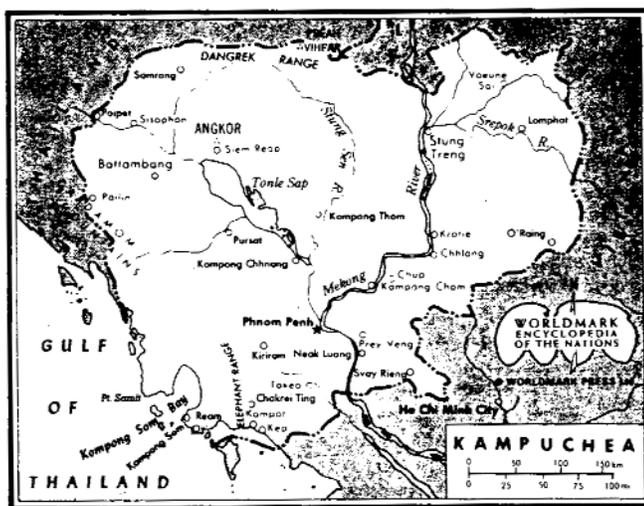
During the early 1970s, US 'aid' quadrupled the size of Cambodia's army in a two year period, as we drew it into our quagmire in Vietnam. Starting in 1968, the US launched massive secret bombing raids on Cambodian territory which it claimed was part of the Ho Chi Minh trail, the supply route that North Vietnam was using to channel arms and military equipment to the Viet Cong. In 1970 the US supported a coup which replaced the civilian administration of Prince Norodon Sihanouk with a military regime

headed by General Lon Nol. In part as a result of the massive US military intervention and the destabilizing effect Washington's meddling had on the Cambodian government, the Khmer Rouge guerrilla movement—which had been insignificant prior to US involvement—grew rapidly in strength and in 1975 seized power.

foreign influence. The entire country was turned into a forced labor concentration camp. The mass torture and killing that followed has been dramatized in the film, *The Killing Fields*, which refers to a place outside of the capital, Phnom Penh, where tens of thousands of torture victims met their end. It is said that more than one million Cambodians were killed by the Khmer Rouge during these years.

The 'liberation' of Cambodia in 1979 by the Vietnamese army and the subsequent exodus of refugees to Thailand led to twelve years of civil war with no less than three armed factions trying to overthrow the government installed by the

Vietnamese. In the wake of our tragic involvement in Vietnam, we directly or indirectly supported all factions opposed to the new government. In another example of 'the enemy of my enemy is my friend' policy, which has mired the US in so many disasters, we



Cambodia. Worldmark Press Ltd.

From then until 1979, when it was ousted by Vietnamese forces, the diabolical regime of Pol Pot disenfranchised the entire population. Pol Pot's Khmer Rouge made extreme efforts to destroy every vestige of colonialism and

contributed to the emergence of the Khmer Rouge as the strongest opposition military force which demanded, and has received, a piece of the power sharing pie.

After a period of on again, off again ceasefires, a negotiated settlement which includes a repatriation plan for refugees and a proposal for 'democratic' elections under U.N. administration has been signed by all parties and backed by the United States, Russia, China, and other regional powers. Prince Sihanouk has returned to head an interim government, and representatives of the Khmer Rouge are again in Phnom Penh as part of the U.N. coalition. Cambodians I talked to are hopeful, but many of them are also fearful of the possibility of a full fledged return to power of the Khmer Rouge.

The situation is desperate. Economically and politically isolated by the U.S. (which until very recently was still trying to punish Vietnam), the country is in ruin. Those fortunate enough to have paying employment earn an average of US\$7 per month. Health care is practically nonexistent. Life expectancy is about forty two years. Something like 100,000 people are amputees and perhaps as many as 1,000 more lose their legs every month to land mines, placed primarily by the Khmer Rouge. Life goes on.

One day, a Cambodian friend, upon hearing that I was almost 43, smiled and said, "If you lived here, you'd be dead."

Since the loss of my right leg in 1990, I have spent part of each year working on prosthetics research, disability rights, and rehabilitation issues, both here in the US and in other places. In February 1991, I was invited by the American Friends Service Committee (AFSC) to visit Cambodia to consider a job and to help evaluate the efforts of non-governmental organizations (NGOs) in meeting the massive rehabilitation needs of the people in that country.



Kaho I Dang, refugee camp in Thailand. Photo by AHRTAG.

The AFSC has been involved in Cambodia since just after the fall of Pol Pot. Its efforts in irrigation projects at the village level and in the re-establishment of veterinary medicine (water buffalos are the engine of agriculture) have had a miraculous effect on food production in the wake of a regime

where even the possession of Western knowledge was grounds for death. The AFSC was also the first NGO to address the amputee situation and the complete lack of infrastructure. This organization promotes an appropriate technology prosthetic system developed by the French NGO Handicap International (HI).

Handicap International was founded by Jean Baptiste Richardier in response to the great demand and scant resources for artificial legs in the camps for Cambodian refugees established along the Thai border in the early 1980s. The organization's approach is to establish basic workshops in which technicians

and amputees themselves fashion artificial legs using locally available materials such as buffalo hide, wood, rubber from old automobile tires, and a bit of steel. It's the same system outlined by David Werner in the prosthetics chapter of *Disabled Village Children*.

The Handicap International leg stands

alongside the Jaipur foot as one of the most exciting examples of enabling 'appropriate technology' in today's rehabilitation landscape. I was eager to see what I had so long promoted among prosthetic practitioners and participants as the kind of creative thinking which could teach a

thing or two to the so called 'advanced prosthetics' of western industrialized nations.

I seriously doubted that I'd trade my carbon fiber, thermoplastic, titanium leg for one made of water buffalo skin, wood, and tire retreads, but this did not keep me from recognizing the value of the efforts at exploring advanced prosthetic ideas within an appropriate technology context. I'm sure these efforts can open doors to better legs everywhere. It's altogether wonderful and shouldn't really be so surprising that some of what is being practiced in the so called developing nations amounts to a lot more than what Dr. Sethi, the inventor of the Jaipur Foot, describes as "blurred Xerox copies" of what's being done in the West.

As an amputee and as a health worker, I found the visit to Cambodia provoked many thoughts. One especially, which keeps coming back to me, is that while I went to Indochina expecting to be primarily concerned with 'hardware', I kept coming back to 'software' issues. I had thought that the greatest contribution I might be able to make would be in the area of making and teaching others to make prosthetic appliances. In the wake of this visit, I am not so sure.

My first days in Phnom Penh with Art Foreman (the AFSC's prosthetist at Wat Than, the National Rehabilitation Center) were more or less what I had expected: dis-

cussions of thermoplastics versus lower tech buffalo hide, of the desirability and feasibility of changeable alignments, etc. These are real and important concerns, and I was impressed with Art's efforts to advance the technical aspects of prosthetic practice in a very difficult environment. That said, from the standpoint of someone who is disabled, I have to wonder if some of the assumptions, methods, and apparent goals of the current rehabilitation efforts need to take a hard look at the reality of day-to-day life for disabled people in this country, at this time.



Welding the device in Cambodia. Photo by John Fago.

One morning, during a lecture to a group of students at Wat Than who were training to be technicians, I asked what was to become an all-too-common question: why was I the only disabled person contributing to the discussion? The first answer usually was that no qualified disabled candidates could be found. This is inaccurate and unacceptable.

That very afternoon, I was struggling to weld a device I had developed in Ajoya, Mexico (see facing page). It's really just a

clamp which enables technicians to rotate a plaster cast during modification. A below the knee amputee on crutches came up, watched me for a couple of minutes, and then gently but firmly took the torch from me and finished the job with a master welder's touch. He then went on to fabricate five more devices quickly and skillfully. Here was a disabled person with exceptional mechanical and hand skills. He told me that he had been trained as a welder and mechanic before his amputation, but that he had been unable to find work because he is an amputee. He was hanging around the workshop while he waited for a leg.

When I pressed my question about the failure to include disabled people, the second answer I got was even more distressing. I was told that to elevate the status of and create a 'professional' standing for prosthetic techni-

cians it was desirable to concentrate on able bodied candidates, because 'good' people would be more likely to enter the practice if they did not have to work in an environment where disabled people were seen as equal.

While I was still reeling from this revelation, I was taken to visit the Maryknoll vocational rehabilitation building at Wat Than. In the first room we entered, there were perhaps 12 or 15 amputees seated at ancient typewriters. They rose as a group and surrounded me,

A Story of Design Improvements in PROJIMO's Prosthetics Shop

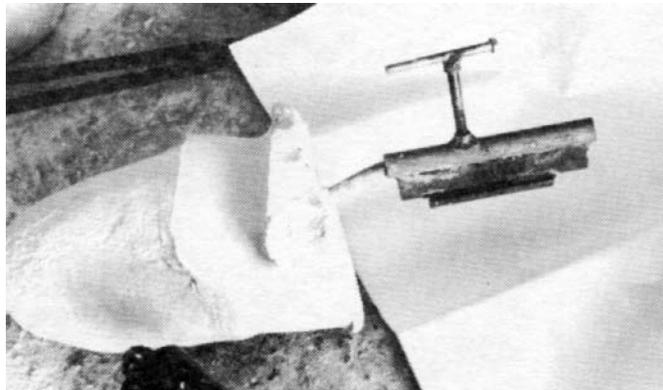
by John Fago

In the fall of 1990, I made my fifth trip to Project PROJIMO since 1986, when I went down for the first time to take photographs for *Disabled Village Children*. In the interim, with support from Hesperian and the Shen Foundation, I've gone through the graduate program in prosthetics at the UCLA School for Rehabilitation Medicine. On subsequent visits I've done everything from making artificial legs and teaching advanced prosthetic techniques to helping repair an irrigation pump. My most recent trip was funded by the Thrasher Research Fund as part of a grant for the development of appropriate technology. This time, besides helping Catalina carry scrub buckets and flowers to the Ajoia cemetery for the Day of the Dead, I tried to improve the process of plaster mold modification used at the PROJIMO prosthetics workshop by introducing some changes in technique and by designing and making a tool to rotate the plaster molds.

The first step in the fabrication of an artificial leg is to wrap the residual limb (stump) with plaster bandages. After this cast has hardened and been removed from the stump, it is poured full of fresh liquid plaster and allowed to harden again, forming a 'positive' model of the stump. In the US and other developed nations, professional shops place a length of one half inch plumbing pipe into the wet

plaster before it hardens. With this extension, the mold can be placed in a holding device, which allows the practitioner to spin the mold with one hand to review overall progress and determine the next area which needs attention. With the other hand, she can easily tighten or loosen the grip on the pipe, as she reviews her progress. In the US, these devices typically cost about \$150. In Mexico, they do not exist.

While it is not hard to find a piece of plumbing pipe in Ajoia, the iron reinforcing bar that is used with concrete in construction is the cheapest and more readily available choice. When the mold is complete, with a piece of 're-bar' extending out of it, you simply clamp the re-bar into position



The device. Photo by John Fago.

between the jaws of a large vise and go to work making your modifications. For a small below-the-knee mold this is fairly easy, but for a larger above the knee mold that can weigh 20 or even 30 pounds, it is a frustrating chore. I observed that the difficulty in rotating and repositioning large molds proved to be a significant obstacle to getting good and thorough modifications.

It seemed like a step in the wrong direction to try and completely change the use of re-bar in the plaster molds to more expensive and harder to find plumbing pipe. I discovered

that the re-bar would slide snugly into a short (say eight inch) section of 3/4 inch plumbing pipe. By welding a piece of L shaped angle iron along the pipe (so that it could be held firmly in place with the vise), drilling a hole in the pipe, and then welding a nut over the hole so that a bolt could be tightened down on the re-bar inside the plumbing pipe (or be easily loosened to rotate the mold for overviews and repositioning), I hoped to produce a device which would make modification easier and just more fun. After all, this is such an important part of the prosthetic process and it can be extremely satisfying or horribly frustrating.

As Marcelo and I were finishing up our prototype, Xavier came in from the orthotics shop where they also modify plaster molds that have a piece of re-bar sticking out of them. He took one look at what we had constructed and went straight to the scrap pile to collect parts for a copy of the device. In half an hour he had made one for himself, and in an hour he was using it back in the orthotics shop. When I saw him later that day across the playground, he winked at me and smiled.

During my visit to Cambodia a couple of months later, I noticed that the workers at the National Rehabilitation Center workshop were using square pieces of wood sticking out of the plaster molds. This meant that the workers could not rotate the molds to get an overview, and could only place them in the vise in four positions. Iron re-bar was readily available. After I fabricated a device like the one we had developed in Ajoia, and my amputee friend had made several more, they were quickly adopted and effectively used by the workers. ■

one plunking himself down on the ground to touch and examine my carbon fiber lower leg. Their eyes were full of questions, but there was silence until the one who had been so intensely checking out my leg looked up and spoke. Cham Ran, our able translator, looked at me and said, "He wants to know what it's like to be disabled."

In some ways, that's the most haunting memory of the trip. Most of the disabled people we met spend their lives waiting. Even the ones lucky enough to have worked their way through the bureaucratic maze and gotten an artificial leg generally still wind up waiting to regain a life. I would bet that none of the amputees seated at the typewriters in that depressing room will ever earn a nickel as typists. They were there waiting for lunch.

I consider myself extremely fortunate. I'm sometimes embarrassed by how little of an imposition I find the loss of one leg to be. Sure, I'd give most anything to get a real one back. But I've been lucky enough to have had a sequence of steadily improving prostheses, and I could live my life happily on any one of the past three or four. That said, I do hope they keep getting better, and I hope even more that my attitude and outlook both continue to grow. It seems clear that the opportunities that appear are to a large degree the result of the way in which we look at the world. The 'rehabilitation' process is, in large part, learning to see new possibilities.

Empowerment. The extent to which rehabilitation succeeds is the extent to which it enables individuals to see new, creative possibilities and extend their lives out into them. It must be done mentally as well as mechanically. In our finite, temporal selves, every one of us lives with limitations and every one of us continually rediscovers a creative attitude to dodge, duck, or overcome them. Creative magic makes life worth living.

During my visit, I was invited to attend a meeting of the heads of the prosthetic efforts of the American Friends Service Committee, the International Committee of the Red Cross, and Handicap International. It was essentially an NGO summit meeting to carve up the prosthetic turf in Cambodia for the next few years. The efforts of the past decade were reviewed, and possibilities for collaborative future efforts were discussed.

At one point, I was asked if I would like to add anything to the discussion. Again, I asked why there was no one present from any of these organizations who could contribute, firsthand, the perspective of the disabled. I wondered why the disabled were not being encouraged to organize themselves as a force in the shaping of the future of the rehabilitation process in Cambodia. At this time, there was not a single disabled person in the administration of the Ministry of Social Responsibility, which runs the National Rehabilitation Center.

Clearly, rehabilitation is seen as something that is done to the disabled, not by or even with them.

When it came to comment on the present state of hardware, I spoke highly of Art Foreman's efforts in the AFSC to evolve the basic Handicap International design to include thermoplastic sockets and changeable alignments. But to my surprise, I found an almost total opposition on the part of Handicap International to changing the basic, highly identifiable design or components of their legs. I like and greatly respect Jean Baptiste Richardier, but I find that HI's apparent insistence on continuing to use only the crudest material components makes little sense in a world where every village has a video machine and other 'hard currency only' blessings from the industrial present. I cannot help but wonder if desirable technical evolutions are being suppressed a bit in the name of past success and an organizational reluctance to change.*

While one meets many dedicated and sincere expatriate workers in Cambodia and other parts of the world, I fear that too much NGO energy serves to 'empower' bureaucracies and not the disabled individuals those bureaucracies are supposed to be serving. In addition, I've observed that the administration of rehabilitation programs by the 'able bodied' too often focuses on appliances or

**Since then, I have learned that Handicap International has changed this position and is now exploring the use of thermoplastics in new and creative ways.*

components of vocational rehabilitation, which in themselves are probably not the most important parts of discovering 'what it's like to be disabled' and how to get on with a creative and productive life.

Handicap International is justly proud of the amputee technicians in their refugee camp shops. This is good, but as far as I could tell, they have no disabled persons in any of their expatriate administrative positions or among their Thai employees in Aranyaprathet or Bangkok. This is not to dismiss the wonderful efforts of everyone over there, but again and again, I saw able bodied people explaining to the disabled 'what it's like to be disabled.' I saw many people with artificial legs, but few of these seemed to have really regained a life.

A most wonderful exception is a man named Son Song Hak, whom I met at Site 8 (one of many Cambodian refugee camps along the Thai border) thanks to Handicap International's remarkable Susan Walker. Hak lost his leg above the knee at the age of nineteen, as a Khmer Rouge soldier. His is a typical story: mother dead, invalid father, two younger brothers, war torn country, the only means available for Hak to get rice for his family was to join the army, which, as bad luck would have it, in his province meant the Khmer Rouge. Less than a year later, he stepped on a land mine. He made his way to the refugee camps along the bor-

der, where he received a Handicap International leg and went on to become a technician, and later, the Director of the prosthetic workshop at Site 8.



Photo from Handicap International

An excellent technician, Hak developed a prosthetic knee which, though more difficult to construct, is generally acknowledged by the HI people to be superior to their standard knee. A couple of years ago, Hak, who by this time had a wife and two children, withdrew from the relative security of his employment with HI to start the Khmer Handicapped Association, where I spent the day of March 7, 1991. This association is principally a school with a current enrollment of about 200 students. Most of the students are disabled, but quite a few of them are able bodied Khmers from the camp. The school's basic mission

is to teach (dare I say, more useful) vocational skills like electronics repair. But interestingly, Hak told me that among the best attended classes at the center were those in music appreciation—both traditional Khmer and Western classical.

I arrived at the camp shortly after nine thirty in the morning, found Hak, and was with him until after four in the afternoon. Almost instantly our conversation established common agreement about aspects of disability and approaches to rehabilitation that are consistent with the current discussions in the independent living movement here in the US and internationally.

After a couple of hours of getting to know one another, I asked Hak what I could do to support his efforts. It was a great pleasure to spend the rest of the day editing a proposal he hoped to use for fundraising. Hak is an excellent writer and a clear thinker. One of his phrases that sticks in my mind was a cautionary note about avoiding rehabilitation programs which "make the disabled lose the good habit of self reliance."

After I had gotten started, Hak excused himself and returned shortly on crutches without his artificial leg. When I inquired why, he explained that he had an ongoing problem with an allergic rash on his stump. Though we briefly discussed some things he could try to alleviate this condition, he was far more interested in having me

edit the proposal he was writing in English to try to raise money to support the expansion of the association. With a smile, Hak added that though he had been informed that an 'important' person was coming to visit him, he hadn't expected that it would be a friend. The leg was necessary to see an 'important' person, but it wasn't for the presence of a friend.

So why am I telling you this story about a one legged Cambodian who lives in the midst of mine fields on the Thai border? Well, I think there is something in music appreciation and friendship that has a lot to do with discovering 'what it's like to be disabled.' I think that in looking squarely at what lingers in the wake of our efforts, we may see that spending time nurturing creative play and consciousness of possibilities is every bit as essential as hardware. When David Werner spends three days in Africa scrounging up parts and making a wheelchair with a vertical cross section of health workers, from white collar desk jockeys, to dirty fingernails technicians, to disabled people themselves, I think that what he accomplishes is far more significant than just the wheelchair.

Back at the prosthetic summit meeting, the head of prosthetics for the International Committee of the Red Cross, Alain Gerishon, listened to the past efforts of the American Friends Service Committee and Handicap International and then proceeded to blow everyone out of the water by describing his group's

plans to spend a small fortune building a central factory run by expatriate professionals, which would crank out what is essentially a thirty-year-old European design for artificial legs, to meet the needs of urban amputees. When the ICRC comes into a country and spends millions of dollars on a factory which can only be run by expatriate (neo colonial?) supervisors, and which is doomed to fail the moment foreign aid is withdrawn, is this a service? Without the elements of creative 'software' and consciousness raising, these dollars only create a dependency on a rehabilitation delivery system that effectively disempowers disabled persons and prevents them from having creative control and coming up with their own diverse solutions.

Life is not a business. Rehabilitation should be pursued in the context of a creative community. It should be fun, and it should make this a better world. Half jokingly, I call my efforts "New Legs for Nomads," because we are all nomads. We are all hunters and gatherers, wandering through transient civilizations. One of our only true possessions is the inspiration we bring to the solution of the puzzle each moment presents. Along with the technical or "hardware" part of rehabilitation; we must address the software component.

Sometimes I wonder if our aid dollars would not be best spent by sending troupes of disabled acrobats out into the world to entertain and educate. I do not deny the importance of hardware; I use it

every day. But without a sense that this hardware is there to serve a life that has possibilities and options, what is the point?

On my return to the US, most everyone I met wanted to tell me the news that our government had announced it would give Vietnam one million dollars for prosthetics. While this is a step in the right direction, in as much as we are finally acknowledging some responsibility, the money will almost certainly be misspent. As with energy issues, I'd say that saving legs is a far more cost effective approach than producing more of them. Dispatching a couple of divisions of US Army engineers to mine sweep Vietnam (and Laos and Cambodia) would surely net a greater number of able bodied people than providing token support for the mechanical side of crude rehabilitation systems that on balance are more inhibiting than empowering for the individual.

The leg I wear is blue and has a Thai dragon decal on it. Other of my legs have been decorated with gold sparkles and eyeballs. None of them looks like a 'real' leg, but they sure do function. When I travel, I wear shorts so that people can see the leg work. My leg may not 'look normal,' but it gets me where I need to go. When I arrive at the National Rehabilitation Center in Cambodia on a motorcycle, or travel across Peru and Bolivia with a blind friend, the people I meet smile because everyone knows that this is a world with many obstacles...and everyone realizes that attitude is everything. ■

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An Important Message to Our Readers

Dear Friends,

Over the last two decades, we have been bringing you thoughtful reporting on health and health-related issues in the Third World, through our Newsletter from the Sierra Madre, with very minimal financial support. However, given the funding difficulties that non-profit organizations such as ours are facing in today's economically troubled times, we are finding it increasingly difficult to continue producing and bringing this newsletter to you.

We have always asked for donations for our newsletter. Many of you have heard our pleas and have given generously. Now, however, we have realized that in order to continue producing three issues each year, we need more consistent support from all of you. Thus, in this issue we are asking you to send in your first yearly subscription of \$12.00 (if you have not already done so) so that you may receive the three issues we are planning for 1993. If you do not send in a subscription (or let us know you can't afford one so that we can make special arrangements for you), we will assume you no longer wish to receive our newsletter and we will take you off our mailing list. For \$25.00, we will add a gratis subscription, in your name, for a health worker in the Third World who can't afford a contribution, but would like to continue receiving our newsletter.

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