Newsletter from the Sierra Madre #37
May 1998

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

HEALTHWRIGHTS
Workgroup for People's Health and Rights

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

DISABILITY AND POVERTY IN THE PHILIPPINES:

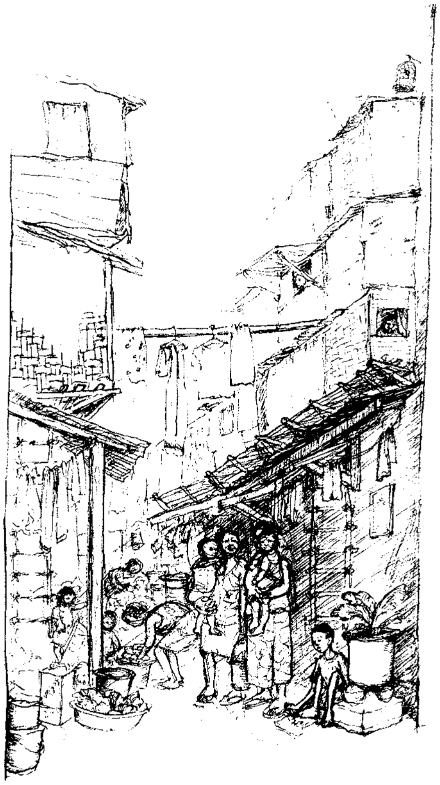
EFFORTS OF FAMILIES TO COPE

CBR workshops in the Philippines *In January 1998, Stichting Liliane Fonds (SLF), a Dutch foundation that helps disabled children in difficult circumstances, held two 3-day workshops in the Philippines. More than 130 SLF mediators from many islands participated. "Mediators" are volunteers, backed by local organizations, who find disabled children with urgent needs and arrange for them and their families to get essential support from SLF. The mediators are often nuns, community leaders, social workers, nurses, or other persons who have a concern for the well-being of disadvantaged children. However, many mediators have little knowledge or training in the field of disability. One purpose of these workshops, therefore, was to introduce mediators to the concepts and practice of community based rehabilitation (CBR)—with hopes that they might take a more enabling, integrative approach to meeting the needs and possibilities of disabled children.*

SLF invited David Werner to help facilitate these workshops. Before the workshops began, he and the Liliane coordinators spent several days visiting some of the SLF-supported children in their homes, first in urban slums of Manila, then in rural and semi-rural communities in the southern and northern provinces of the Philippines. Here, David shares with readers some of the events and circumstances which impressed him most deeply.

Disabled children in the stacked shanties of Manila

I have visited a lot of poor countries and seen many difficult living conditions. But urban poverty in the Philippines is among the most dire I have witnessed. Poverty in Manila's inner city seems more extreme because—unlike the shanty towns on the "septic fringe" of many mushrooming cities—here the poorest families live wedged into the faults and crevices of conspicuous wealth, much of it controlled by foreign corporations.

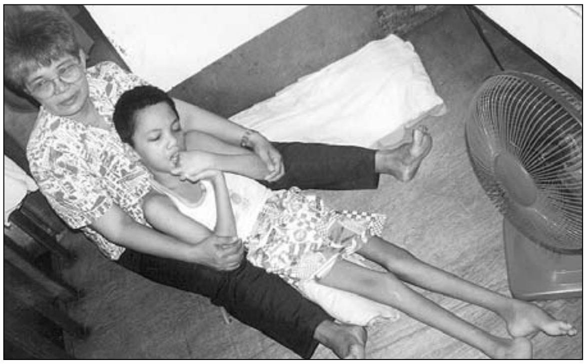


One of our first field visits in Manila was to a central-city area with many high-rise hotels and industrial buildings. Neon signs and sumptuous window displays deck the street-fronts. But the alleys between the buildings look like human beehives—or termite colonies—with thousands of tiny cellular dwellings plastered precariously against the high brick walls. In each alleyway, a narrow central path, about 2 feet wide, separates the shacks on either side. Made of bamboo slats and cardboard, most of the shacks consist of a single room, about 6 by 8 feet square. Each shack lodges a whole family. On top of the first layer of shacks balances another layer of similar shacks, then another and another In some alleys the shacks are stacked precariously 5 or 6 stories high.

No exit for Rocky. A mediator in one of these poor urban "barangays" (communities) in central Manila took us to visit several of the disabled children whose situation, she said, was especially difficult. To reach one child, named Rocky, we squeezed along the narrow path down an alley, ducking past drying clothes, stepping over debris and babies. We entered a ground-floor hut (greeting and apologizing to its occupants on our way by) and climbed a series of steep, rickety ladders that zig-zagged upward through the living quarters of one family after another. At last we arrived in the tiny one-room hut where Rocky's family lives. About 14 years old, Rocky had cerebral palsy with profound mental and physical disability. His gaunt body extended stiffly with spasticity. He could not roll over by himself or grip things with his hands. He spent the daytime lying naked on the bamboo-pole floor of the shack. (Lack of clothing made the afternoon heat more bearable in the small, window-less room.) His mother hurriedly pulled some shorts onto his thin stiff body.

It was hard to know how aware Rocky was of his surroundings. He could not speak, and his mouth was twisted in a position of long-term discomfort. His mother clearly loved him, and did her best to comfort and care for him—when she was home. But because she worked part time and Rocky's brother and sisters went to school, until recently Rocky had been spending hours each day alone.

The mediator had brought together families in the neighborhood who had disabled children, to discuss their needs and explore ways to assist each other. As a result, a warm-hearted woman from the next alley came to visit Rocky for an hour or two every day. During these visits, she would hold his stiff upper body tenderly in her arms, stroking, rocking, and talking to the child. As she did so, Rocky's distorted mouth would gradually relax and a look of peace would enter his eyes.


The neighborhood visitor lovingly holds Rocky in her arms.

What more can be done for a child like Rocky? Had we visitors seen Rocky in a clinical setting, we might easily have made misguided suggestions. We might have suggested regular visits to a community center for disabled children (since one was located not far from the home). We might have recommended a wheelchair, or wheeled cot, adapted to accommodate Rocky's stiff body, so that his family could take him for walks and outings to provide stimulation and activity. However, on visiting Rocky's home, we realized how unrealistic such recommendations would be. In the cramped living quarters, even a wheelchair that folded would take up too much space. And it would be impossible to maneuver along the narrow, cluttered paths of the alleys. With a wheelchair or without, to get Rocky in and out of his tiny elevated room, up and down the rickety ladders through the shacks of those on the floors below, would be a major and risky feat. For the same reasons, trying to take him to the community center several times a week would be virtually impossible for his mother.

Yet, how often are mothers blamed for "non-compliance" by professionals who have no idea of the difficulties the families face? We realized how important it is for staff of rehab programs to visit the homes and neighborhoods where disabled persons live. Only then can they adjust their recommendations to both the possibilities and limitations of that reality.

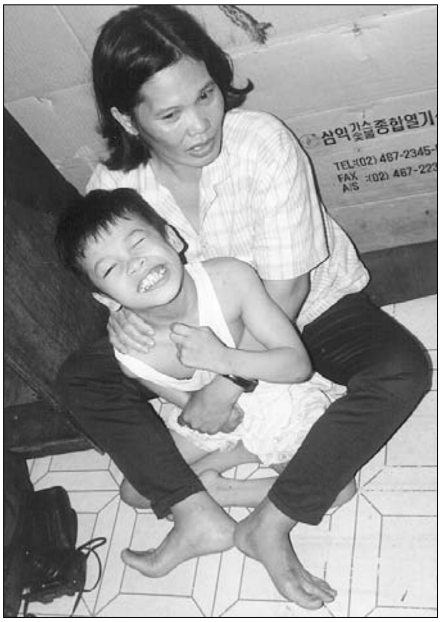
The challenge of community-based rehabilitation is to creatively try to overcome or cope with the negative aspects of the situation, and to identify and build on whatever is positive.

On the negative side, for Rocky, home was in some ways a trap—so confining that the family's options were severely limited. The real trap, of course, was poverty. As long as Rocky's family lived in such a barely accessible shack, providing a wheelchair or arranging visits to a rehab center would likely create more difficulties and frustrations than it would solve.

On the positive side, in low-income Philippine neighborhoods there often exists a *strong sense of community*—a spirit of caring and sharing that has withered in many urban areas around the world where (in the words of the poet Wordsworth) "neighborhood serves rather to divide than to unite." A welcome characteristic of many Filipino people is that they take pleasure in reaching out to help a neighbor or friend—even a stranger—in need.

Thus, especially among the families of other disabled children in this barangay, the mediator was able to start building a network of caring, understanding support.

Such a neighborhood support network, if encouraged and further developed, may be one of the most favorable solutions for a child like Rocky, and his family. It is difficult to say how much Rocky, who has extensive brain-damage, would benefit even from the "best" therapeutic program available. His combined mental and physical deficits may substantially limit his potential for functional development. In some countries, such a child is often separated from his family and institutionalized. But whether that is a kinder answer for child or family is highly questionable. What Rocky clearly needed, perhaps more than any programmed therapy or professional intervention—was *caring human contact:* the simple intimacy of a loving voice, smell and touch. The closeness of his mother (intermittent though it was) and the daily visits by the big-hearted neighbor who spent hours gently holding Rocky, talking and singing to him, may do more to satisfy Rocky's core needs than any institutional care.


This mother of a girl with cerebral palsy intuitively uses her arms and legs to position her stiff body.

We agreed that the mediator for this barangay was off to a good start. She had found a way to bring caring persons into the home where it was so hard to get Rocky out. Perhaps the family and home visitor could learn a few personalized exercises and activities to help improve Rocky's flexibility and comfort. Or if they could explore ways to position him so that he could observre his surroundings and be fed more easily, this might be another step forward.

One simple but important suggestion to make Rocky more comfortable was to provide him with a soft pad so that he would not have to lie directly on the bamboo slats. Sometimes small things can make a big difference.

Holocaust in Manila's alleys

We visited a number of disabled children living in conditions of poverty similar to those of Rocky. Time and again we were struck by the bountiful love and innovativeness of these children's parents, especially their mothers. One big obstacle to doing more for their disabled child was lack of money—sometimes simply the lack of fare for transport to school or clinic.

Fortunately for some very poor families, Liliane mediators are able to allocate modest funds to help them start an income-generating or income-supplementing activity. For example, a mother who has to work outside her home may be given modest seed money to help start up a small store or sewing service in her own home. That way, she can earn some money while staying at home with her disabled child.

Such funding assistance from an organization like SLF can only go so far. It helps a number of low-income families with disabled children to cope more independently. But in terms of the larger picture, such measures—while important and sometimes life-saving for the children selected—are like a finger in the dike. A more far-reaching, sustainable solution needs to get at the roots of the underlying problem.

Those of us visiting the Philippines were deeply struck by the extensive, extreme poverty side by side with enormous wealth. **It became clear to us that the biggest obstacle to the well-being of disabled children is rooted in the cruel inequality between social classes.**

Life is hazardous for the poor, especially for the destitute families living in such crowded, vulnerable conditions. On seeing disabled children like Rocky, where any attempt to move them from their tiny, upper-story shacks is a slow and risky undertaking, we worried about their safety and survival. Surely, we thought, the alleys crammed with hundreds of cardboard and bamboo shacks were like a giant tinder-box awaiting conflagration. "Don't these crowded settlements ever catch fire?" I asked the mediator.

"Oh yes!" she exclaimed. "Sometimes the managers of the industrial buildings and hotels on either side of the shacks start a fire to clean out the alleys. They see the squatters only as a nuisance. You can't imagine the human disaster caused by such fires—the deaths, severe burns, new disabilities, homelessness for hundreds…!"

"Are the fire-starters punished?" I asked, naively.

She shook her head and shrugged sadly as if to say, "Business is business."

The Root Problem: Dire poverty in a land of plenty

As we traveled through urban and rural areas in the Philippines, we began to realize that the torching of shanty settlements in Manila's alleyways "to keep the commercial zones safe and attractive" is the tip of the iceberg of ruthless imbalance of wealth and power. Yet, the problem is not so much Filipino as global—the consequence of institutionalized unfairness and greed that stem back to colonial times but have become more overbearing with the current globalization of the economy.

Having lived and worked in Mexico for many years, I was struck by the historical parallels between the Philippines and Latin America: the occupation and conquest of proud indigenous peoples, first by the Spanish and then by the United States.

Today, the domination of the Philippines by the USA, economically and in some ways culturally, is striking. Sign-posts and bill-boards of American multinationals, ranging from Coca Cola to Marlboro, dominate the landscape. Clothing, haircuts, and popular music follow the latest US fads. Giant shopping malls replete with glitzy consumer goods cater to those who can afford them, and to many who cannot. Clearly, there is a lot of prosperity in the Philippines, as conspicuous and disturbing as the widespread poverty. The gulf between rich and poor is appalling. On leaving the inner-city squatter camps of Manila, we drove through plodding traffic past the shipping port, and then past a huge exclusive yacht harbor with thousands of moored luxury yachts, worth many millions. The contrast is astounding.

In spite of the sumptuous wealth in the Philippines, abject poverty—and the diseases of poverty—remain widespread. High rates of malnutrition among children and the continuing high incidence of diseases such as tuberculosis are typical of countries with a Gross National Product (GNP) much lower than that in the Philippines. Furthermore, the current trends of structural adjustment, with privatization of public services and cut-backs in food and health subsidies for the poor, further aggravate the hardships of the underclass.

In an SLF workshop, Ernesto--who was born with no arms--shows mediators how well he can write.

Rural poverty and foreign wealth. For the mass of people in rural areas, land-shortage and deprivation are also severe. Yet, as we flew over the Philippines from one tip of the archipelago to the other, I was stuck by the enormous productivity of the land. Hundreds of miles of rice paddies glow florescent yellow-green in the tropical sun. Rich soil and plentiful rain in most of the islands foster an agrarian abundance capable of meeting all the people's basic needs. The surplus of produce could easily provide social security and a healthy standard of living for all people. In addition to bountiful agriculture, the Philippines also have vast mineral resources. With fairer distribution of what the land provides, poverty could easily be eliminated; poor health and the high incidence of disability could be drastically reduced. The country is a Cornucopia. If the land and waters were fairly and sustainably husbanded, no child would need to go without adequate housing, health care, schooling, or the opportunity to realize her or his full potential.

But reality is disturbingly different. Fair distribution in the island nation remains a smoldering dream. During a brief interlude there was hope of far-reaching change. In 1986, millions of Filipinos in a peaceful uprising overthrew the opulent dictator, Ferdinand Marcos. But they did not and could not overthrow his powerful foreign accomplice: the US government in league with the multinational industrial complex. So, despite changes in the Filipino presidency, the brutal imbalances continue and in some ways have worsened.

More and more of the best land in the Philippines is being purchased by multinational agribusiness and mining industries. In the southern island of Mindanao, we visited villages where land-hungry peasant families live crowded into tiny bamboo huts and their children suffer from the diseases and disabilities of hunger and poverty. There is an unusually high incidence of children with brain damage resulting from premature birth by undernourished mothers, or resulting from high fever and "meningitis" because the children's resistance is low, again because of poor nutrition. Hunger in a land of plenty!

As we flew into the airport of General Santos, at the south end of the island, we passed over a volcano where the surrounding landscape, as far as the eye could see, was a homogeneous blue-grey carpet. "Rainforest?" I asked, doubtfully.

"No," was the reply. "Pineapple. Dole Pineapple!" The Dole Fruit Company of USA now owns the majority of high quality land in the southern islands. And as its land holdings keep expanding, the poor are crowded into the remaining, poorer quality land. The best fruit is exported. The lucrative profits, taxed at absurdly low rates, leave the country to fill coffers in the USA. As multinational agribusiness increases its profits by replacing farm workers with fossil-fuel-guzzling machines, more and more people become jobless. As competition for jobs rises, wages fall. Destitute peasants migrate to the slums and crowded alleys of the cities where, in turn, job competition drives wages down and rent up.

Meanwhile, foreign mining companies are ravenously invading the Philippines. Big money corrupts in a big way. In violation of land reform laws of its own Constitution, the Philippine government now permits foreign mining companies to stake unilateral claims on the nation's best mining land. Foreign mining industries now have applied to purchase 27% of the total land area of the Philippines!

Add all this together and it is easy to see why—despite the country's vast resources and the spirit of caring and sharing which is still a hallmark of so many Filipinos—the country remains plagued by high rates of poverty, disease and malnutrition-related disabilities.

The tragedy of the Philippines is the story of many poor countries. Globalization of the economy—spearheaded by GATT, the World Trade Organization, and the pending Multilateral Agreement on Investment (MAI, see p. 11)—is relentlessly expanding the universal sovereignty of multinational corporations while reducing the sovereignty of disadvantaged nations to defend the rights and livelihood of their own people. The situation in the Philippines today—with a widening gap between rich and poor, accompanied by cutbacks in public services, growing unemployment, and falling wages—is a pattern repeated to greater or lesser extent worldwide.

Personally, I came away from the Philippines with mixed feelings. On the one hand I was deeply moved and inspired by the efforts of mothers and families, against great odds, to find ways to protect, nurture, and stimulate the development of their disabled children. And I was enormously impressed by the dedication, energy, and caring of the SLF mediators to help disabled children and their families find ways to cope with extreme poverty, discover provisional solutions, and to become more self-reliant in spite of huge obstacles.

On the other hand, I was deeply upset by the human suffering resulting from gross inequality and perpetuated by a neocolonial system that, rather than working toward sustainability of humanity and the planet, aspires to the economic growth of the already wealthy, in spite of the enormous human and environmental costs.

In conclusion, I left the Philippines convinced that for the immediate succor and well-being of individual children with special needs, a program of urgently needed assistance like that of Stichting Liliane Fonds is of vital importance. But for the long-term quality of life of these children—and, indeed, for the whole of humanity—a worldwide awakening is necessary, a peaceful revolution, or evolution, leading to a global community based on fairness, equal rights, and equal opportunity for all.

Story from the Philippines: Lorenza Starts a Community-Based Initiative

In the northern province of Kalinga, the local mediator, a nun named Aurora, took us in a truck to a remote mountain village. There we visited the home of Lorenza, a woman with two disabled girls. Kanaruffa, 14 years old, was microcephalic and had epilepsy. Sherilyn, 1½ years old, had cerebral palsy, was visually impaired, and had almost no head and trunk control. When Sister Aurora had first visited the home, she found Kanaruffa tethered with a rope during part of the day. The Sister had insisted the child not be tied up. Lorenza had complied. But in talking with Lorenza, we learned that untying Kanaruffa had in effect tied down Lorenza. She had tied the girl to keep her from hitting and injuring her defenseless baby sister—and to keep her from wandering off and getting lost, which she had often done. Since she could not let Kanaruffa out of her sight, Lorenza was now home-bound. She had abandoned her role as village health worker, which had required visiting the homes of the sick. This meant less income and food for the family. (Lorenza's husband, a woodcutter, earned too little to feed the family adequately.)

The visitors from SLF were impressed by Lorenza's quiet determination and commitment to her family and community. Because she was already a village health worker, and seemed to have an intuitive ability to assist her multiply-disabled baby, the visiting SLF team thought she could become an excellent village rehabilitation worker. So they invited her to attend the upcoming 3-day workshop in Manila, with all costs covered. At the workshop Lorenza could also take part in making a special seat for her baby. Then, through the skills she learned, she could help make seats and assistive devices for several other disabled children in her village.

While we were visiting Lorenza's home, other families with disabled children began to arrive. Some Sister Aurora had seen before, others not. Among those arriving was a teen-age girl named Sheryl, who was nearly blind.

Sheryl holds Lorenza's baby, Sherilyn, lovingly. Sheryl, like Sherilyn, is visually impaired.

Sheryl was bright and dreamt of doing something worthwhile with her life. She had completed primary school against great odds and had begun secondary school, but had dropped out because of difficulties. Now she mostly just stayed at home, helping with a few chores. She said she often felt depressed.

In the course of the discussion, various possibilities emerged. Sheryl showed interest in Lorenza's baby, perhaps in part because she identified with the baby's visual impairment.

When Lorenza asked Sheryl to hold the baby, Sheryl did it so lovingly that the baby, sensing the positive feelings, relaxed and almost smiled.

This was the germ of a beneficial relationship for all concerned: for Sheryl, Lorenza, her children, and the whole community. Arrangements were made for Sheryl to come to Lorenza's home daily to help care for the baby and the older girl. This would free Lorenza to resume her work as a village health promoter, and do community rehabilitation work as well. If things worked out as hoped, Sheryl could learn health and rehabilitation skills from Lorenza, and gradually assume a valued role in her community.

What had seemed an unpromising situation was suddenly budding with possibilities.

The Manila CBR Seminar-Workshop

The Manila Seminar and Workshop for SLF mediators was especially challenging because there were so many persons taking part—by the last day, more than 100. This made a fully participatory approach difficult. But by dividing into small groups, virtually everyone was able to contribute.

One goal of the seminar was to help mediators realize the importance of full involvement and leadership by disabled persons in the programs and decisions that affect them—and especially in Community Based Rehabilitation initiatives.

Mediators, with the help of a child, learn to make assistive devices.

Therefore the organizers made a point of inviting leaders from various organizations of disabled persons, as well as disabled staff from the programs of the mediators.

The first day was mostly spent by giving the mediators a chance to listen to and question these disabled persons about their priorities, needs, and wishes—as well as obstacles they faced in achieving full participation in society. They described the ways they were succeeding in surmounting certain obstacles, and gave ideas for how SLF mediators might assist in this process, especially with disabled children.

A discussion followed of the relative strengths and weaknesses of existing CBR programs and of the Independent Living Movement. The group agreed on the importance of combining the strengths of both approaches: the strong leadership and self-determination of Independent Living, together with the commitment to include all disabled persons, especially those who are poorest and least able to defend their interests, which is a strength of CBR.

The second day, the mediators met in small groups with disabled children and their parents. The purpose was to listen to the parents and children about what they considered to be their aspirations and concerns. Rather than focus on the biomedical needs of the children (which is what happens too often in conventional rehabilitation), they were encouraged to take a more holistic approach, exploring the full needs of the child, ranging from food and housing, to play and interaction with other children, to schooling, skills training, work, and full participation in society. Some parents wept as they described the difficulties they encountered. But at the close of the sessions, they expressed thanks for the opportunity to be listened to so attentively…and by a group of educated persons and professionals!

For the disabled children who could express themselves in words, the opportunity was unique. Some who were at first withdrawn and reticent to speak, when they discovered they were not only listened to but taken seriously by a group of adults, opened up and discussed their biggest fears and dreams.

This more comprehensive, or holistic, approach to the needs and possibilities of disabled children is consistent with the evolving priorities of Stichting Liliane Fonds, which places increasing emphasis on the social aspects of rehabilitation and integration. To this end, SLF is currently designing new report forms for planning and recording the progress of the children helped through mediators. Kees van den Broek, Director of SLF, led several brief sessions to discuss the purpose of the new (still experimental) report forms, and to gather useful feedback from the participants. The new forms are designed not only for reporting progress, but also for helping the mediator design a comprehensive approach to meeting the full range of the child's needs.

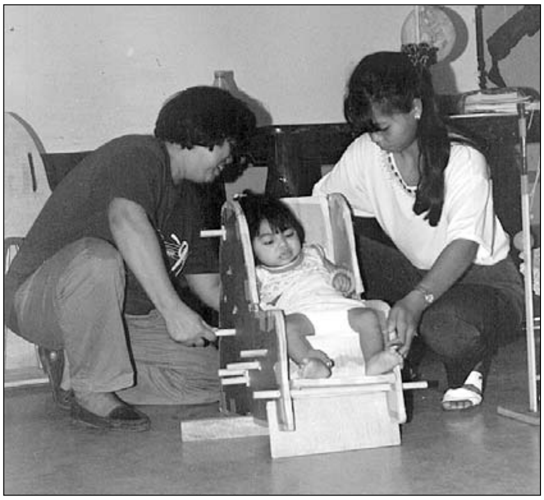
Another important activity of the second day was to introduce the concept and practice of "Child-to-Child." Through Child-to-Child, school-aged children learn thoughtful ways to respond to different health and development needs of their younger brothers and sisters, and of children with special needs. Participants watched color slides from PROJIMO in Mexico, where school children learn to appreciate disabled children for their strengths, not their weaknesses, and where children with different disabilities learn to help each other. (Examples were given from our new book *Nothing About Us Without Us,* which was made available to all the mediators.)

The third (last) day of the seminar involved a hands-on workshop in which the mediators, in 6 small groups, worked with a dozen disabled children and their parents, designing and building simple assistive equipment.

This learning-by-doing activity was held at House Without Stairs, a famous skills-training, income-generating program for disabled youth in Metro Manila.

In this remarkable program hundreds of persons, many disabled by spinal-cord injury or polio, produce assistive devices ranging from wheelchairs and hand-powered tricycles to walkers, standing frames, and orthopedic appliances. They make furniture, crafts, and educational toys. They also do piece-work on contract for different industries. Most of the heads of the shops are disabled, take pride in their work, and are good role models for newcomers.

The first step of the assistive-device workshop (which actually took place on the second day) was for each group of mediators to meet with the disabled child and his or her parents, to explore what the child (and/or parents) most wanted to accomplish (within realistic expectations) in the near future. Next, the group tried to design an aid that might help meet that expectation. Together the mediators, parents, and the child (when possible) drew a picture, on poster paper, of the device they hoped to make. Then, in a plenary session, the different groups gathered to present their various designs and to invite everyone to suggest improvements.



Mediators made an adustable cardboard seat for Lorenza's baby.

The next step was for each group of mediators, parents, and child (as much as was possible) to collectively build the device. For many mediators and parents this was a totally new experience. Many were unsure of their abilities and nervous about taking part. But, once they started, they discovered they were able to do far more than they had expected. As the process was demystified, their confidence grew. The husband of one mediator, a local carpenter, and a couple of parents who were skilled craftspersons, made important contributions.

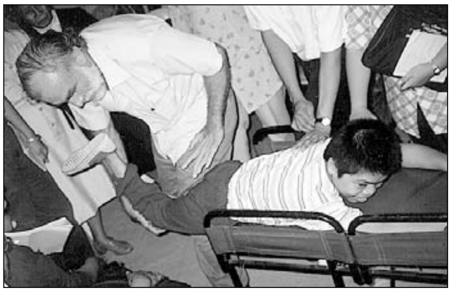
For a one day apprenticeship workshop, the results were impressive. Equipment made comprised several special seats, including one adjustable cardboard seat made for Lorenza's baby. Lorenza helped to design and build this seat and other equipment, and in the process learned important skills which she could subsequently put to good use in her village.

With the help of the disabled workers of House Without Stairs, designs were made for wheelchairs and a hand-powered tricycle, adapted to meet the needs of several disabled children attending the workshop. The House Without Stairs team committed themselves to building the wheelchairs and making sure that they meet the needs of the children who will use them.

Another piece of equipment included unusual parallel bars for an eight-year-old girl with spastic/athetoid cerebral palsy. On trials with the girl, the group found that when she stood, her arms lifted stiffly, against her will, to the level of her shoulders. Try as she might, she could not lower her arms to the normal height of parallel bars. The group experimented with different heights and widths of bars (first holding them by hand in different positions) until the girl found the position she felt comfortable with. Then they made a set of movable bars in the position preferred by the child. In the process this girl, who had at first been frightened and non-cooperative, gained self-confidence and participated to her best ability.

The final step of the workshop was a plenary evaluation. The different groups and children involved demonstrated the equipment they built, and everyone could make suggestions.

Perhaps the most impressive accomplishment of the workshop involved two boys, both with diplegic cerebral palsy, who had never been able to walk. The older boy, Roldan, who was 17 but looked about 13, had been told by doctors that he had polio. He had very spastic legs tightly bent at the knees. Since he had been told he would never be able to walk, his request was for a "racing wheelchair."



Mediators check Roldan for hip contractures to see if he might be able to walk with an assistive device.

On physical examination, however, the group found that Roldan had a powerful upper body and remarkably good balance and coordination. When the group explained, "We think there is a good possibility you could learn to walk with leg-braces and crutches," Roldan gasped in disbelief. But when they asked him if he would like to experiment with standing and walking, he was thrilled and eager.

They started by making a walking frame, or "parapodium." They cut an upright piece of plywood as high as Roldan's chest, and attached this to an oval footboard, to which they attached a cardboard leg-separator extending from above his knees to his feet. They strapped Roldan to the parapodium while lying down, gradually straightening his stiff knees until they were almost straight. Then they stood Roldan up. He stood between two tables, tipped on their sides to simulate parallel bars. In a few minutes, Roldan learned to "swing through" on the bars, bearing his weight on his powerful arms. He was so happy he whooped. The group explained to him that if he strapped himself onto the frame and practiced walking every day, in time the contractures of his knees would stretch and he would be able to stand straighter. Then he could graduate to braces and crutches. "And pretty soon, with your strong arms and good balance, you will fly!" Roldan could scarcely believe it.

With the younger diplegic boy, Domingo, it was a similar story. But it was easier, since his knees straightened more readily. At first Domingo was reluctant to try a walking frame. But Roldan, thrilled by his own success, urged him on: "Look at me! If I can do it, so can you!"

In the final evaluation session, the 2 boys eagerly demonstrated how they could walk, proudly swinging through between the two tables. Had the group had time to find or build crutches, it was clear both boys could have graduated to crutch-use that same day.

Then came the biggest surprise. I (David) asked Domingo if he could stand with the frame, without holding onto the tables. Not fully understanding my English, the boy thought I was asking him to walk without using his hands. To everyone's amazement he lifted his hands in the air and rocking his weight from one side of the oval base of the parapodium to the other, managed to teeter himself forward in step-like fashion. Everyone cheered.

At the end, the two boys, glowing with new-found pride and confidence, expressed their appreciation. They felt empowered by the group problem-solving process in which they had been included and listened to as equals.

Then in big-brotherly fashion, the older boy, Roldan, turned to Domingo. He encouraged the younger boy never to give up, to stay in school and study hard, so that one day he could get a good job, help others, and show the world that disabled people deserve equal respect.

This was truly the spirit of Child-to-Child at its best. The workshop came to a close, with everyone inspired by the discoveries and successes of the disabled children involved. They were also animated by their discovery of their own, previously unrecognized abilities and possibilities. They found that with modest resources and a few simple tools they could make a difference in children's lives and abilities. They learned that this is easier, more empowering and more fun when mediators, parents, children, and members of the community work together as equals in the problem-solving process.

If they learned nothing more, the SLF seminar/workshop can be considered a success.

Roldan proudly walks with his new parapodium, while Domingo waits his turn. Wooden beds turned on their sides function as parallel bars.

Story from the Philippines

Girls with Brittle-Bone Disease from Mindanao and Mexico Become Pen-Pals

In the southern island of Mindanao, in the district of Marbel, we visited a tribal area where the people are very poor but their village, constructed almost entirely of bamboo, has a traditional harmony with the landscape. There we visited the hut of a family who have three little girls with brittle-bone disease (osteogenesis imperfecta), a congenital condition in which the bones break very easily, and the limbs become twisted and deformed. This tends to make weight-bearing and walking increasingly difficult and finally impossible.

In their bamboo hut, Mercy, Rosalie and Jenny meet with visitors from SLF, while curious village children look on.

Seeing the 3 girls in this Filipino village reminded me of a girl with osteogenesis imperfecta in Mexico, who is also sponsored by Liliane. Virginia, too, is from a poor family, but through Project PROJIMO has had various forms of assistance from an early age. For years she was able to walk, but now uses a wheelchair. (At her request, the PROJIMO team adapted a removable table for her wheelchair at a recent SLF mediators workshop in Mexico).

Now 17 years old, Virginia is finishing secondary school, and is determined to study to be a secretary.

None of the 3 girls could now walk. Two were sitting and one lay on the elevated bamboo floor of the hut. Not used to strangers, the 3 girls were at first frightened and shy. Gradually they warmed up. The oldest, Jenny, was the most spirited. Yet she had a sort of brooding anger, especially toward children outside the family, whom she said were mean. (During our visit, the windows and doorways were crowded with faces of curious village children, whom Jenny often snapped at and tried to shoo away, to little avail.) Fifteen years old but tiny for her age, Jenny had never been to school, but her mother and younger brother had taught her to read and write.

The next oldest girl, Rosalie, about 9 years old, was very shy and looked miserable. She lay on her back and moved very little. The girls' father, who was dressed in rags and had a kind face, said he was worried about Rosalie, who had been lying that way for 3 months. She never sat up because her back hurt so much when she tried. We concluded that Rosalie probably has a fracture of the spine.

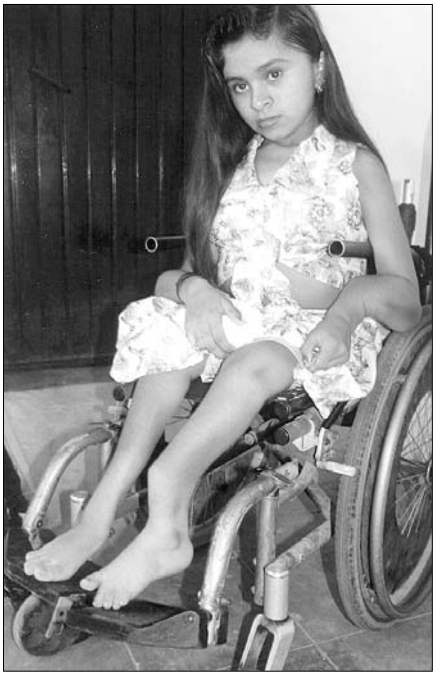
Jenny demonstrates how well she can write, while Mercy watches. The 3 sisters are eager to become pen pals with Virginia in Mexico, who also has the brittle-bone condition.

This will likely mend in time. But she also had developed a chronic cough and looked ill. The biggest danger now was stasis pneumonia, which can develop from lying in one position for a long time without moving. (The father explained to us that a fourth daughter had already died from a similar condition.)

We suggested that Rosalie try to take deeper breaths. She tried. The local mediator made a note to bring Rosalie a toy flute, so that by playing it she would move more air in her lungs. But most important was to help Rosalie change her position regularly and begin to sit up. Because of the pain, this would have to be a gradual process. We tried gently slipping a board under her back, and slowly inclining her up. But we succeeded in raising her only a few degrees before she whimpered. A decision was made to build a small, padded, adjustable reclining couch for Rosalie, which could be gradually angled from a lying to a sitting position. (In fact, a few days later the couch was made by the local mediator and her group during the workshop in Davao.)

The isolation of the 3 girls from children in the village was a concern. The mother of another disabled girl volunteered to start a Child-to-Child project, helping the village children to understand the difficulties of the 3 sisters and to look for ways to include them in games they could safely play. The children sometimes play a board game called "Damas." In the Davao workshop, a group of mediators made the board and chips for this game, so that the village children could use it to play with the sisters.

In order that the 3 sisters in Mindanao and Virginia in Mexico feel less isolated, share experiences, and become long-distance friends, we have arranged that the girls on either side of the Pacific become pen-pals, writing to each other (through interpreters) and exchanging drawings and photos. Especially for the Filipino sisters, who rarely have a chance to leave their hut, this interchange with a girl with a similar disability, in a different land and culture, should help to extend their horizons, lighten their hearts, and give them courage to make something of their lives, just as Virginia is doing. It should bring a bit of joy and adventure into all their lives.



Virginia, in Mexico, is eager to become a pen pal with the sisters in the Philippines. She now has a desk-top, adapted to her wheelchair in PROJIMO.

PROJIMO UPDATE

Better accessibility for bus travel

One of the benefits of the new *Skills Training and Work Program* in the village of Ajoya, Mexico, is that it has brought in some exciting new perspectives and possibilities.

To launch the "Wheelchairs for Children" workshop, 3 wheelchair-riding graduates from PROJIMO have come from afar to teach villagers the basics of wheelchair design and construction. (This is a welcome reversal of the conventional roles, insofar as here disabled youth are the skilled instructors of unskilled non-disabled apprentices.)

The 3 disabled instructors have ideas of their own. All are from humble origins, but they have spent time living in cities and exchanging ideas with disabled activists in Mexico and the USA. They have thus garnered new insights and a strong sense of their rights.

Polo teaches a non-disabled youth to make wheelchairs.

Polo Leyva, a wheelchair builder with dreams

Polo Leyva is a local villager who had polio as a baby and has never been able to walk. He spent his childhood playing in the sand outside his family's hut. He never went to school. But when PROJIMO—the village program run for and by disabled young people—began 17 years ago, Polo was invited to participate. Disabled wheelchair engineer, Ralf Hotchkiss, taught him how to build wheelchairs, and for years Polo headed PROJIMO'S wheelchair and welding shop.

Eventually Polo left PROJIMO to strike out on his own. His travels led him to Hermosillo, where he set up a wheelchair repair shop with an organization of disabled youth. He now lives in Tijuana, is married, and is currently negotiating with officials for a piece of land to set up a wheelchair-making and repair shop in that city. Polo's dreams have carried him far. But he was more than willing to come back to Ajoya for a few months, to help PROJIMO's new Work Program start its worker-run cooperative to produce children's wheelchairs.

A ramp for access into village busses

For wheelchair riders and other physically disabled persons in Mexico, getting in and out of busses has always been difficult. Polo Leyva, who travels a lot by buses, is determined to see his country achieve greater accessibility ... starting with Ajoya.

He was tired of having to ask people to lift him into busses in their arms. From the time he arrived in Ajoya this February, Polo began to talk with villagers about the need for a wheelchair ramp to make it easier to get into and out of the busses.

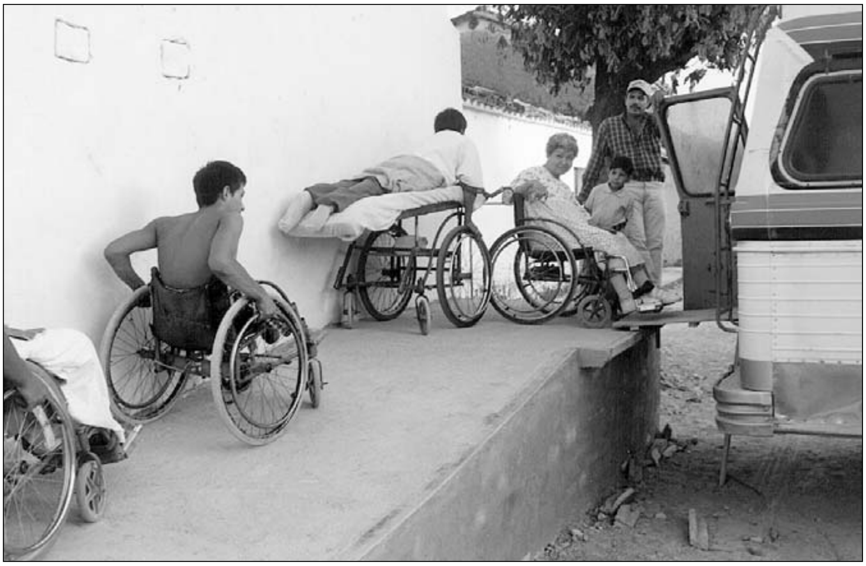
At last the village responded. Under the guidance of the 3 disabled instructors—Polo Leyva, Martín Pérez, and Gabriel Zepeda—a group of village youth started building the ramp.

Villagers construct the wheelchair ramp in Ajoya.

With rocks, sand, and cement, the villagers built the ramp against the back wall of a big adobe house by the bus stop. First they built a temporary retaining wall of wood. This they lined with rocks which they cemented together. They filled the enclosed space with rocks and sand, and capped it over with cement.

The long ramp has a gentle slope (a ratio of about 1 to 15). The ramp has 2 level platforms, an intermediate one for access to pick-up trucks, and a higher one for rolling onto the bus. The Ajoya bus has a set of rear-end doors through which wheelchair riders can roll right in from the ramp. A space without seats at the back of the bus allows 3 wheelchair riders to be securely positioned.

Polo hopes many other towns will follow PROJIMO's example and build similar ramps.



News and Activities from the INTERNATIONAL PEOPLE'S HEALTH COUNCIL

The International People's Health Council (IPHC) is a worldwide coalition of people's health initiatives and socially progressive groups and movements committed to working for the health and rights of disadvantaged people. The vision of the IPHC is to advance toward health for all — viewing health in the broad sense of physical, mental, social, economic, and environmental well being. If you want to learn more about IPHC, become part of the coalition, or communicate with the regional IPHC coordinator in your area, contact either David Werner at HealthWrights, or the global coordinator of IPHC, Maria Zuniga, at CISAS, Apartado 3267, Managua, Nicaragua (Fax: 505-2-661662; e-mail: cisas@ibw.com.ni).

A Surge of Interest in the Effects of Globalization on Health:

IPHC and our book *Questioning the Solution* ahead of their time on these issues

1998 is the 20th anniversary of the celebrated Declaration of Alma Ata, which affirmed that *health is a universal human right*, and set the goal of "*Health for All by the Year 2000." Primary Health Care* was promoted as the comprehensive, participatory, and in some ways revolutionary strategy to reach that goal.

Now, close upon the year 2000, it is painfully clear that humanity is still very far from reaching Health for All. Over one billion people have no access to essential health services and, worse still, don't have enough to eat. There is growing awareness that current macro-economic policies—often referred to as "Globalization of the Economy"—have in many ways had a negative effect on both the global environment and the health and well-being of a substantial portion of humanity.

Since the beginning of the 1990s groups like the International Forum on Globalization and People's Development Center have been trying to raise awareness of the high human and environmental costs of unregulated economic growth, and to mobilize a grassroots movement to work toward a more equitable and humane development model.

But until recently, activists and NGOs criticizing globalization have been comprised of mostly progressive economists and development workers, without much involvement of the health sector.

At last there is emerging from within the health sector a growing concern about the obstacles to Health for All that are a consequence of an inequitable, profit hungry global economy. Since the early 1990s the IPHC was like a voice in the wilderness on these issues. But within the last few months, suddenly concern has proliferated. Three important events are now in the formative stage:

1. The Norwegian Organization for International Development Cooperation (NOVIB), with Dr. Eric Ram (former head of the Christian Medical Commission) is launching a coalition of over 100 non-government organizations called GLOBAL HEALTH WATCH.

2. The World Health Organization (WHO) is planning a follow-up GLOBAL FORUM AT ALMA ATA, KAZAKASTAN, to evaluate what happened to the vision of Health for All. The planners recognize that globalization of the economy, which has led to a widening gap between rich and poor, must be critically examined, and healthier alternatives sought.

3. In Galveston Texas, October 26-28, 1998, a major conference is planned by WHO, Pan American Health Organization (PAHO) and University of Texas, on the theme of "HEALTH & DEVELOPMENT IN THE NEW GLOBAL ECONOMY: EXPERIENCES OPPORTUNITIES AND RISKS IN THE AMERICAS."

We are delighted that key members of the International People's Health Council have been invited as planners and speakers to each of these 3 vitally important events. The book *Questioning the Solution: the Politics of Primary Health Care and Child Survival,* written by David Werner and David Sanders of the IPHC, provides a wealth of background material for those looking at the impact of economic policies on health. (A review from South Africa of this timely and important book is reprinted on the following page.)

We urge all those who are concerned with the future health of today's children and the future of life on this planet, to join the IPHC and other networks and coalitions that are watch-dogging world trends and working toward healthier, more sustainable alternatives.

Announcing a groundbreaking publication:

The New World Order: A Challenge to Health for All by the Year 2000

PROCEEDINGS OF THE CONFERENCE HELD AT THE UNIVERSITY OF THE WESTERN CAPE IN CAPE TOWN, SOUTH AFRICA ON JAN. 29-31, 1997
Published by Health Systems Trust, 504 General Building, Durban, South Africa
Available from NPPHCN/SAHSSO, PO Box 192, Gatesville 7700, South Africa, and from HealthWrights for US$7.00

These papers focus on issues of key concern for events such as the 2nd Alma Ata Conference, soon to be held in Kazakastan (see above), and for the newly conceived NGO consortium "Global Health Watch."

The conference was led by the International People's Health Council (IPHC), the National Progressive Primary Health Care Network (NPPHCN), and the South African Health and Social Service Organization (SAHSSO).

The book includes papers by D. Werner, M. Chossudevsky, J. Seaman, D. Sanders, A. Sambo, V. Shiva, R. Davies, P. Bond, B. Ashley, F. Baum, D. Beltran, B. Ekbal, Z. Chowdhury, V. Biruta, and I. Friedman.

"Essential reading for all those concerned with health policies and people-centered development!"

BOOK REVIEW

Questioning the Solution; the Politics of Primary Health Care and Child Survival

By David Werner and David Sanders, Review by Rosemary Harbridge

Reproduced (slightly abridged) from the Australian and New Zealand Journal of Public Health, 1998, VOL22 NO 1

A core part of *Questioning the Solution* is an in-depth critique of oral rehydration therapy (ORT) as a treatment for diarrhoeal disease in children. This seems a most appropriate choice, since diarrhoeal diseases are a major feature of child health and mortality in developing countries.

I enjoyed the choice of title. In *Questioning the Solution,* the authors not only question the use of western models of selective health care practices in attempting to provide solutions to Third World health problems, they also—in using packaged ORT as an example—question the very content of the packages: i.e. the ORT solution. The authors question the promotion, distribution and marketing of pre-packaged ORT solution, when other less expensive and more appropriate oral rehydration methods, such as home made solutions of salt and sugar, or cereal-based drinks, are available and are proving to be more suitable.

Using specific examples and case studies, the authors provide a comprehensive explanation of how and why—in spite of the 1978 Alma Ata Declaration on primary health care (PHC) and goal of achieving "Health for all by the year 2000"—the world's population is getting sicker and more poverty stricken by the day. The social, economic, political and environmental factors which are the root causes of disease are discussed. Detailed descriptions of PHC programs which have worked in spite of these negative forces are provided.

After briefly detailing the evidence that "global programs have failed to adequately reduce the continuing high rates of malnutrition, illness and death among third world children," the book introduces us to the tragedy of the cycle of poverty, illness and death with 'Rakku's Story.' This is an abridged version of a story by Sheila Zurbrigg, based on events in rural India: a mother's struggle to save the life of her child, who has severe diarrhoea. Rakku has other children to feed, and her sole income is from working long hours in the fields for the local land owner. She is therefore not able to breast-feed her baby, and must leave it all day in the care of her young daughter. When the baby becomes really ill, she decides to take it to the city to the hospital. In doing this, she loses a day's wages (all she has with which to feed herself and her other children) and she also risks losing her job. She sells the last of her possessions to pay for the bus fare. On seeing the doctor, she is scolded for not bringing the baby earlier, and is given advice about the importance of breast-feeding. She is also given a prescription for medicine, which she obviously cannot afford. After the baby receives intravenous fluids, she is sent home. The baby's condition worsens on the way home, and by the time Rakku gets home, the baby is dead.

Werner and Sander's book poses the question: "What caused Rakku's baby's death?" Working on the premise that "the way we define the causes of human ills often determines the solutions we seek," the authors show that the real causes of ill health are not being addressed on a global scale and how primary health care and the ideals of Alma Ata have been undermined internationally.

> **While few dared say publicly that the Alma Ata model of primary health care was subversive, almost from the time of its conception there were choruses of important voices proclaiming that it would not, could not, and did not work.**

The first part of the book covers the background to PHC in 3 aptly named chapters: "The historical failures and accomplishments of the western medical model in the third world;" "Alma Ata and the institutionalization of primary health care;" and "The demise of primary health care and the rise of the child survival revolution." The latter describes the shift in the 1980s from comprehensive to selective primary health care, and the role of UNICEF in promoting this change.

This period is further dealt with in chapter 13, which discusses the role of the World Bank and the International Monetary Fund in undermining the development of primary health care. [We see how] the structural adjustment policies of the World Bank and the role of multinational corporations contributed to the demise of the ideals of primary health care. The history, however, is still in the making. The final chapters give the reader some excellent and detailed examples of programs where primary health care principles have been applied. These are examples of equity-oriented initiatives which have been able to make improvements in the health of communities [often] in spite of fierce opposition from local vested interests, repressive governments, and multinational corporations. Health status gains have been made as a result of programs such as Project Piaxtla in western Mexico, where the root causes of disease, such as landlessness, lack of political power, and poverty have been addressed.

It is easy to become disheartened at the lack of progress towards the "health for all" goals espoused by the Alma Ata Declaration, and one might feel even more despondent after reading this book. The information and descriptive detail which is presented helps the reader to come to grips with the forces which lie behind the international scandal of preventable poverty and disease.

This reader was left with the conviction that the principles of primary health care are intact, and with a better understanding of the reasons why they are often thought of as being unworkable. If primary health care is not working, it is not because the idea is not a good one; it is because it is dangerous to the interests of those who control most of the world's wealth, and thereby most of the world's access to good health.

It is easy to agree wholeheartedly with Albert Einstein (quoted in the frontispiece):

> **Not until the creation and maintenance of decent conditions of life for all people are recognized and accepted as a common obligation of all people and all countries—not until then shall we, with a certain degree of justification, be able to speak of mankind as civilized (p. iii).**

The final chapter calls for a "grassroots united front for world health," stresses the need for a "child quality of life revolution," and suggests ways in which health workers and ordinary citizens can contribute to these movements.

This is a very readable, well produced text. The information and ideas presented are both thought provoking and action provoking. It is well referenced for those who wish to read further, and well chosen illustrations help to highlight the main points throughout the text.

Rosemary Harbridge
Northern Territory Library, Darwin, Australia

An important new booklet on human and sustainable alternatives for development:

THE POST DEVELOPMENT READER, COMPILED BY MAJID RAHNEMA WITH VICTORIA BAWTREE, 1997

PUBLISHED BY ZED BOOKS, 7 CYNTHIA STREET, LONDON NI 9JF, UK. TEL: (0171) 837-4014; FAX: (0171) 833 3960

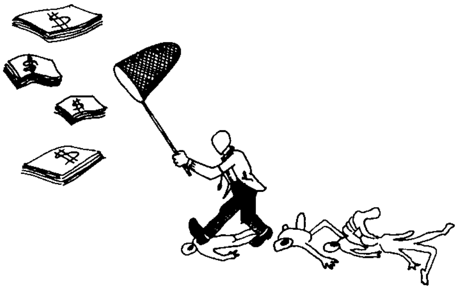
This timely book brings together essays and exhortations by some of the world's most visionary and pragmatic thinkers and activists, past and present, who have worked toward people-centered and equitable paradigms of development—or better, "*post development.*" Included are provocative writings of such social analysts and change-agents as Mahatma Gandhi, Ivan Illich, Helena Norberg-Hodge, Susan George, Vandana Shiva, Vaclav Havel, Gustavo Esteva, Jerry Mander, Graham Hancock, Sub-Comandante Marcos, Ashis Nandi, Eduardo Galeano, and others.

This collection of essays is essential reading for all who are concerned about—or have an influence upon—the future well-being of humanity and the planet.

Global Warning: *Watch out for MAI!*

More Power to the Multinationals, Less to the People

With each new global trade agreement, economic globalization is disenfranchising a larger portion of the world's poor and middle class. From GATT (Global Agreement on Tariffs and Trade) to the WTO (World Trade Organization) to NAFTA (North American Free Trade Agreement), global accords are stacking the deck for further concentration of wealth and power. Now a new proposal for the global economy is being discussed: MAI (the Multilateral Agreement on Investment). Fortunately, concerned citizens worldwide are organizing to prevent MAI from becoming a reality. But it will be an uphill battle!



What is MAI?

MAI is a new treaty now being negotiated by the Organization for Economic Cooperation and Development (OECD) in Paris. If passed, it will give unprecedented powers to global investment bankers, money speculators, and transnational corporations. It will turn present-day regulatory processes upside-down. Instead of governments regulating corporations, MAI will regulate local, state, and national governments. It will invert the balance of power between corporations and governments. More than ever, corporations will govern the global economy.

To avoid public scrutiny, for more than two years, MAI has been planned behind closed doors. Its framers know that because it supersedes federal, state, and city governments, citizens everywhere would protest. Unquestionably, MAI will promote globalization. The dispute is over what kind of globalization. Will MAI benefit broad sectors of the population, as its proponents claim? Or will it exacerbate the problems that have emerged with economic globalization over the past 25 years, including greater income inequality, soaring unemployment, and declining living standards for most of the world's labor force?

How MAI strips local control

MAI specifies that foreign companies must be treated the same as national companies. For example, let's say your city now favors locally owned businesses in contracts for municipal projects such as public works, roads, or school lunches. Or perhaps your country only allows local residents to own land. MAI could override all such rules. Even non-discriminatory laws can be overridden if they limit foreign entry. For example, to protect endangered resources your government might restrict all corporations—domestic and foreign—from starting new mining or timbering operations. Foreign companies could challenge these limits, claiming they favor local companies that are already established. The effect will be to bypass laws to protect the environment.

Corporations as "Most Favored Nations"

Under MAI, corporations gain a status equivalent to "Most Favored Nations." Had MAI been in force during South Africa's apartheid system, all government sanctions and boycotts against South African investments would have been illegal. Thus MAI would eliminate one of the most effective tools for human rights and environmental activism.

MAI would enable corporations to sue governments for monetary compensation in the event that a law violates investor rights as stated by the agreement. International investors could choose to sue a country before an international tribunal rather than in the country's domestic courts.

Thus MAI provides new rights for corporations without corresponding rights for labor or the public. It limits the ability of governments to carry out policies to promote local employment and economic development. This is, again, the kind of globalization that has contributed to increasing poverty and income inequality over the last two decades.

NGOs make their case

On October 27, 1997, 47 Non-Governmental Organizations (NGOs) from 23 countries met in Paris to consult with the OECD. The NGOs argued that **MAI presents big obstacles to sustainable development and to the sovereignty of nations.** They explained how **MAI will weaken environmental, consumer health and safety regulations** around the globe, and will **undercut the bargaining leverage of Third World countries against powerful multinationals.** They protested that the exclusion of the developing nations from negotiations would bias the MAI against the needs and objectives of those countries.

These NGOs see MAI as a dangerous leap past other treaties. In the words of the OECD itself, it confers "state of the art" rights upon transnationals. Rather than to increase the rights of powerful multinational investors, what is needed is an international framework for regulating foreign investment.

The OECD has agreed to conduct a literature review of the impact of foreign investment on the environment and to review how the MAI might affect international environmental agreements. But the negotiators refused all other NGO demands. They still plan to complete the agreement before June 1998.

At their press conference the next day, NGOs announced a coalition against the MAI, and launched an international campaign to prevent adoption of the agreement.

Local communities fight back

The public is slowly growing aware of the dangers of agreements such as MAI. On April 20, 1998, the Board of Supervisors of San Francisco, California, voted unanimously to oppose the MAI and "similar international accords that could restrict San Francisco's ability to regulate within its jurisdiction, decide how to spend its procurement funds, and support local economic development."

With this resolution, San Francisco has taken a strong position against future economic pacts that give more powers to international investors while tying the hands of local government. This proactive stance sends free-traders and the White House a much needed reality check: what's good for multinational corporations is not necessarily what's best for working people, the environment and human rights. By thinking globally and acting locally, San Francisco is reclaiming some of the power usurped by corporations' greed.

What you can do

- First, learn as much as you can! Consult the world wide web (see below). Or send $10.00 (if you can) to HealthWrights for a packet of key information, with up-dates.
- Help educate others so that more people are aware of this important issue.
- Organize members of your community.
- Work with your local government to establish MAI-free zones.
- Contact your elected representatives and tell them what you think.

World Wide Web sites
with MAI Information:

Friends of the Earth:
http://www.foe.org/ga/mai.html

Preamble Center for Public Policy:
http://www.rtk.net:80/preamble/mai/maihome.html

Public Citizen-Global Trade Watch:
www.citizen.org/pctrade/MAI/mai.html

Third World Network:
www.twnside.org.sg/souths/twn/twn.htm

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Newsletter from the Sierra Madre #37 May 1998

A bamboo pole between the feet of this girl in the Philippines helps to keep her legs from scissoring.

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Newsletter from the Sierra Madre
was created by:
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