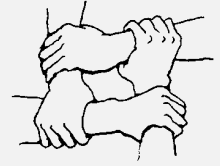




Newsletter from the Sierra Madre #34

December, 1996



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

In this Newsletter we describe a brief training course in Community-Based Rehabilitation in Recife, Brazil. Concentrating on practical activities, participants helped improve the situation of disabled children in distressing conditions—in part by arranging for mentally handicapped girls to help care for physically disabled children. Here we also announce two new books developed through HealthWrights. The first is Questioning the Solution: The Politics of Primary Health Care and Child Survival, which is just off the press. The second, which will be in print in 1997, is Nothing About Us Without Us: Developing Innovative Technologies For, By, and With Disabled Persons. Sample pages from this forthcoming book are included as a preview.

A Hands-on Learning Event in Brazil for Multipliers of Community-Based Rehabilitation - David Werner -

Striking contrasts in Brazil

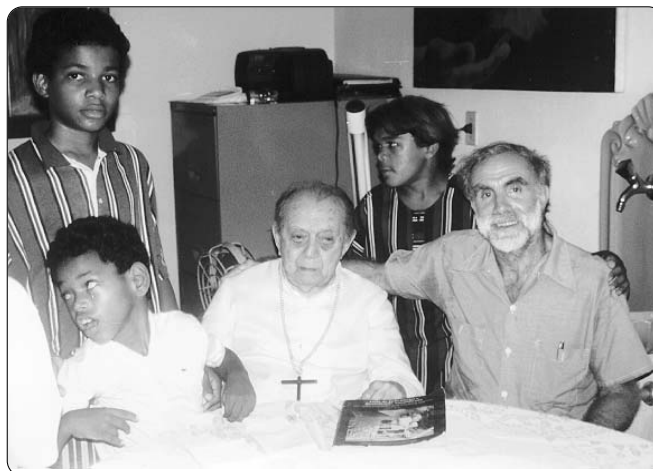
Brazil is a vast country which does not tolerate—but celebrates—DIFFERENCE. With its warmly human yet seductively candid vitality, the country is less a melting pot than a motley collage of races and cultures. A diversity of tropical, temperate, and 'cool' personalities—black, indigenous, caucasian—convive with daunting variations of harmony and discord while passionately preserving ethnic roots and rites.

Brazil has striking contrasts and contradictions. Its history is shrouded by colonial exploitation, the slave trade, brutal military dictatorships, and currently, by a voracious market economy that is further widening the immense gap between rich and poor. Today Brazil is one of the most inequitable countries on the planet: its wealthiest 10% have earnings 32 times that of the poorest 20%; festering favelas surround the heavily fortified, prison-like palaces of the rich; the diseases of over-consumption divert public attention from the overwhelming diseases of poverty.

Because of these enormous injustices, Brazil has been the spawning ground for a spectrum of idealistic

social movements and democratic struggles. Through its *comunidades de base* (communities of poor families based on Biblical caring and sharing), Brazil pioneered the Theology of Liberation. While in Recife I had the privilege to meet 85-year-old former-Bishop Helder Camara, the beloved "pastor of the poor." Long one of my heroes, I still have a quote by Camara pinned over my desk in California. It reads:

"When I give food to the poor they call me a saint. When I ask why the poor have no food, they call me a communist."



In Recife David Werner visited Father Helder Camara, "pastor of the poor" and pioneer of liberation theology. The children are from a family home for abandoned and disabled children, run by father Eduardo Figueroa (see page 6.

Brazil is also the birthplace of the renowned educator, Paulo Freire. During the military dictatorship, he launched an adult literacy program which, through a group process he called *conscientização*, so effectively raised the awareness of destitute citizens that Freire was jailed and then exiled. (He is now once again a national celebrity.)

Freire's methodology of 'education for liberation'-described in his classic book *Pedagogy of the Oppressed*-has been adapted for health promotion throughout Latin America and the world to help communities analyze and organize to correct the root causes of poverty and poor health. In the village health program in Mexico we have made good use of Freire's methods. Our guidebook *Helping Health Workers Learn* devotes a chapter to Freire's empowering methodology.

Today Brazil no longer has a military dictatorship; its leaders are elected. But still the government is full of contradictions. While it promotes certain policies to soften the hardships of the disadvantaged, it caters mostly to the interests of the wealthy and powerful, often at devastating human and environmental cost.

Fighting for disability rights in Brazil: from the bottom up and the top down

To a large extent, improvements in the rights of disadvantaged persons in Brazil have been achieved through organized, sometimes militant, popular demand. For disabled persons, a strong Independent Living (IL) movement has grown up in the larger towns and cities. Together with parent associations and organizations of persons with different disabilities, it has successfully pressured for the passage of laws to protect the rights and enhance opportunities of disabled persons.

Fortunately, Brazil currently has a progressive branch of the Ministry of Justice, called CORDE (Coordination for the Integration of Disabled Persons) which welcomes input from disability organizations. In the last few years, CORDE has taken growing interest in promoting Community-Based Rehabilitation nationwide. In 1995, CORDE held a Technical Seminar on CBR, to which I was invited. CORDE has recently published the first Portuguese edition of *Disabled Village Children*. (The translation was organized by our friend Gene Williams, a disabled activist from Massachusetts who has worked closely with the IL movement in Brazil.)

A Course for 'Multipliers' of Community-Based Rehabilitation

From October 28 to November 1, 1996, CORDE invited me to Brazil to teach a "Course for Multipliers of Community-Based Rehabilitation (CBR)" in the northern coastal city of Recife. The text for the course was *Disabled Village Children*.

When first asked to teach the 5-day course, I had misgivings. The 60 participants (too many for a fully participatory process) were to be government workers active in some sort of rehabilitation or disability-related work. Required to have "at least 3 years of community experience," they were selected from two dozen municipalities of Northeastern Brazil. After graduating from the 5-day course they were expected to become the trainers and multiplicadores, promoting CBR at the community level.

I confess I had serious doubts about such an apparently top-down, government-initiated approach to CBR. In my experience (and I have visited many community programs in different countries), the most successful and sustainable CBR programs are usually start-

ed from below by those who are most concerned: groups of disabled persons and families of disabled children. For this reason I requested that the course include (1) a substantial number of disabled participants (or family members) some of whom should be disabled organization leaders and activists, (2) home visits and discussions with willing, local disabled persons/families living in difficult circumstances, to get their perspective on needs, obstacles, wishes, and ideas for program priorities, and (3) hands-on, problem-solving activities with disabled children and their families, including construction of assistive devices using low-cost local aids designed for and with the individual child. I felt that if the course could help rehabilitation professionals to work together with communities, listen to disabled persons, and relate to them as partners and equals in the problem solving process, much might be accomplished. The goal should be to encourage rehabilitation workers to empower, not merely to prescribe.

Course preparations. I arrived in Recife several days before the course, in order to make plans with the local coordinator. I also wanted to meet with leaders of disability groups and with families of disabled children in difficult circumstances to arrange their involvement as resource persons in the course. One of our visits was to a government-run institution: a hostel for abandoned, severely disabled children. For me this visit was deeply disturbing. I witnessed institutionalized cruelty to helpless children.



Course participants improvised a seat insert to help this disabled child sit in a better position in his stroller.

Though unintentional, this cruelty had become routine and almost acceptable. It stemmed from shortage of personnel, budgetary limitations, official bureaucracy, and the distance of decision-makers from the children affected. The result was to increase, rather than reduce, the children's disability.

The 60 children in this hostel—many with multiple disabilities—are usually cared for by an average of 5 or 6 caretakers at any one time. Several appeared to be chronically starving.



Tiny for their age, they were skin and bones. Their severe wasting (marasmus) was not due to food scarcity but to difficulty with head-control and trouble swallowing. They could take only liquid foods in small sips. To prevent gagging they needed to be correctly positioned and gently spoon fed. Getting enough food into them to satisfy their calorie needs (and hunger) would require a lot of time and patience. The children's caretakers—including nurses and social workers—were loving women who did their best. But with so many multiply disabled children to try to feed, keep clean, and care for, the few caretakers simply did not have the time to adequately feed and mother those children who needed extra help. As a result the neediest children were emaciated and stunted. Apart from a food deficit, they got much less hugging and stimulation than they needed for their minds and bodies to grow. Given the chronic shortage of personnel, even the pediatrician, psychologist, and therapists who regularly visited the program saw no clear solution. The children's situation was stochastically accepted as unfortunate but inevitable. Notwithstanding, these youngsters at least have roofs over their heads and someone to provide a bit of care for them—unlike most of Brazil's millions of hungry street kids.

On arriving at this hostel, we were shown a dozen disabled children lined up on the porch, all sitting in special wheeled seats, or strollers. All the strollers were exactly the same, regardless of the size, spastic patterns, or individual needs of the children. Their canvas seats were held by diagonal metal-tube frames. The children sat passively in a half-reclining position, like sacks of potatoes.

Not only were the stroller-seats failing to provide good positioning or stimulate head and body control, for many of the children the unhealthy positioning was leading to increased spasticity and deformity. A few of the less severely disabled children were able to take a few steps with assistance, but they had no walkers. The one walker we saw was inappropriate and broken.

Given these children's extensive unmet needs, it occurred to me that—with some guidance and the use of their books (*Disabled Village Children*)—the participants in the training course might be able to make simple, individually adapted seats, assistive devices, and stimulating play-things for some of the children. With the help of the staff, we chose 6 children whom they agreed to take to a workshop to be conducted during the course.

The course. Despite my misgivings, the training course was a success. There were a lot of practical, hands-on activities. Divided into small groups, the participants had a chance to meet and talk with parents of disabled children, and—whenever possible—with the children themselves. The disabled participants in the course, many of whom were leaders of disabled organizations, provided a key dynamic. They led discussions about needs and possibilities based on their own experiences.

One day was spent mostly on Child-to-Child activities. In the morning, after watching a slide show from Mexico to spark their imaginations, the course participants first practiced Child-to-Child activities among themselves. They used simulation games, role-plays, and discussions designed to sensitize school-age children to the needs and potential of children who are different. In the afternoon, small groups of participants went into various classrooms of a public school. After some ice-breaking games, they facilitated similar activities with the children. The school kids were at first shy. But once they discovered that the adults actually listened to them and took their ideas seriously, the kids warmed up. They expressed their own doubts and fears concerning disabled persons, acted out role-plays, and asked perceptive questions. At the end of the sessions the course participants asked the kids how they liked the activities, and what they felt they had learned.



Having made a table for a child in a wheelchair, course participants made a high rack from which toys they had made could be hung.

What they said they liked most was the chance to talk openly and directly with some of the disabled participants, some of whom were blind, quadriplegic, or had undeveloped limbs or other marked deformities. The students said that the activities had helped them realize that disabled people are ordinary people like themselves, with the same needs, emotions, and dreams.

The appropriate technology workshop.

Two half-days of the course (one afternoon and the next morning) were spent in a small wheelchair-making workshop run by physically disabled youth in a low-income neighborhood of Recife. The course coordinators and I had visited this workshop before the course started, to talk with the workers about our objectives and to request their assistance. We had explained that we hoped to bring several disabled children from the government hostel (described above), so that in the workshop the course participants could evaluate the children's needs and attempt to make simple, individually-designed assistive devices for each child. The disabled shop-workers were eager to help in whatever ways they could.

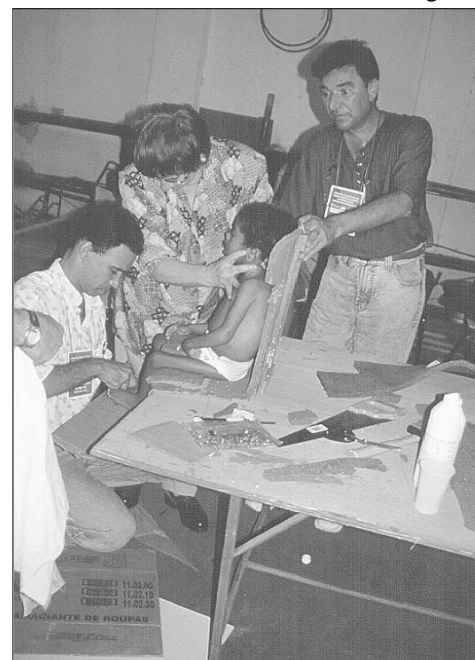
I had my doubts about whether a workshop with so many (60) participants—most of them inexperienced with innovative, low-cost technologies—could work without becoming total chaos. I also worried that with so many adults milling about in a small, hot, non-air-conditioned workshop, the situation might be overwhelming for the disabled children, especially for those who were undernourished and in delicate health.

But my fears were soon calmed. The participants formed 6 groups, each with a bewil-

dered disabled child. But among the participants were many educators, child psychologists, physical and occupational therapist, rehabilitation technicians, disabled persons, and—most important of all—mothers of disabled children. The different groups pooled their resources and rose to the occasion. The mothers first tried to gain the children's confidence, talking gently to them, and then gently beginning to touch the children and take them into their arms. The children, starved for attention and human contact, began to smile and respond. A couple of the course participants with experience in evaluating children's needs and designing assistive equipment assisted me in cir-

culating from group to group. At first most of the participants were afraid to rely on their own observations, and to innovate. But the children's needs were so enormous that the groups began to improvise. The disabled shop workers—whose experience was mainly with construction of metal wheelchairs and walkers—rose to the occasion and began working on innovative designs themselves, in addition to assisting the different groups when their skills were needed.

The end results in the workshop were impressive. Using cardboard, sticks, strips of cloth, and occasional bits of metal bar or tubing, the



A group of participants used metal rods covered with cardboard to make a seat-insert for a multiply disabled child from the hostel.

groups managed to create a variety of quite functional assistive devices for the children, including special seats, wheelchair inserts and supports for improved body position and head control, a hand splint to improve manual function, tray tables, and a variety of colorful toys, which were suspended above a child for stimulation and development of hand-eye coordination. To all appearances, the children appreciated both the attention and the equipment. The staff from the hospital, who accompanied the children, were thrilled by the discovery that important assistive devices could be so easily and simply made. They said that they would make equipment for other children at the institution, and were delighted to receive a copy of *Disabled Village Children* to provide ideas and guidelines.

A survival seat for Enrique. Perhaps the most important-and potentially life-saving-assistive devices created by the course participants at the workshop were the seats and seat inserts that helped position children's bodies and heads so that it would make swallowing and feeding them easier.

One of the children whose needs were most critical was Enrique. Physically completely paralyzed by brain damage at birth, Enrique had been abandoned by his poverty-stricken parents and eventually ended up at the government hostel. Skin and bones, he looked about 6 years old, but we were told he was 14. Feeding him was a big problem, since his body and head were completely floppy, and he had no mouth control. Although unable to move or speak, Enrique's mental ability was apparently intact. However, his only way to communicate was with his eyes. He seemed to understand most questions, and would close his eyes to say no, and leave them open to say yes. Sometimes he almost seemed to smile. And sometimes, when asked questions about the special seat his group was making for him, tears would roll down his cheeks. He appeared to like both the seat and the attention, but would weep with frustration at not being able to communicate more effectively. The participants realized that while they were perhaps able to help Enrique in a small way—and at least make feeding him easier for his care-providers—a lot remained undone. Enrique needed a real home, a loving family, public assistance, and community support.

"And how many other children like Enrique are there in Brazil?" asked one course participant, tears in her eyes.



Sewing together layers of cardboard, course participants made a special seat for Enrique. One purpose of the seat was to make it easier to feed him.

Juao the shop worker. One of the young workers in the wheelchair-making shop had one leg paralyzed by polio and walked by pushing on his weak thigh with his hand.



He wanted to know if anything could be done so he could walk without having to push with his hand (which made carrying large objects more difficult). A group of course participants was assigned to help Juao resolve his problem. The group was encouraged to work with Juao as an equal in the problem-solving process, and not simply to design and make

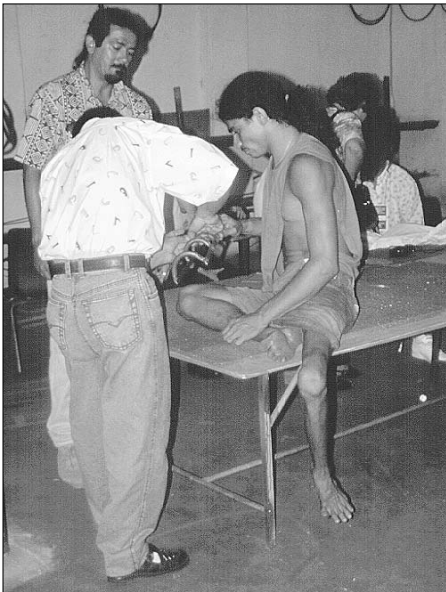
an assistive device for him. "Work with him as a partner, not a patient!"

Examining Juao's leg, the group found that he had a knee contracture of about 25 degrees, which, if possible, needed to be corrected before Juao could walk with a brace. They performed a test to find out whether the contracture was primarily in the muscles or in the knee itself. (If in the muscles, the contracture can often be corrected with exercise, casting, or bracing, to gradually stretch the tight muscles. If the contracture is

in the joint capsule, surgery may be required.) To explain all this to Juao, the group used a life-size plywood skeleton made in PROJIMO (the community rehabilitation program with which I work in Mexico). The skeleton has 'muscles,' made from old bicycle inner-tubes, which stretch and contract as the joints move. This is an excellent teaching aid for demystifying basic anatomy. Juao enjoyed the skeleton act, and said it helped him to understand the functions of his knee.

The group decided that the first step toward improving Juao's walking was to gradually correct his knee contracture with a night brace. Among the course participants was an orthotist (professional brace maker) who helped Juao's group design a simple leg brace which they could make from two long flat metal bars joined by curved sections of metal tube (materials that were available in the wheelchair shop). Juao was the only person in his group with the metal-working skills needed for making the brace. But when the group of professionals started working, the predictable thing happened. Juao was left lying on the examining table, while the others began to cut, measure, and attempt to bend the pieces for the brace. Juao watched passively without comment. Then suddenly, one of the disabled participants woke up and said, "Hey! Juao is more skilled at metal-work than we are. And he knows more about his own leg. Rather than our making the brace for him, he should be making it himself, with our help. That way, if he has to adjust or remake it after we are gone, he'll know how." Everyone agreed. With a grin, Juao climbed off the table and took charge. Opening a copy of *Disabled Village Children*, the group showed him drawings of similar braces.

Juao did an excellent job making the brace. Everyone learned a great deal. But the most important lesson they learned was that of working with the disabled person as a partner and not a patient. This is the key to Community-Based Rehabilitation.



At first the rehab. professionals began to make Juao's metal leg-brace for him.



Later the professionals realized that Juao had more metal-working skills than they did. So they asked Juao to take the lead in making his own brace, which he did proudly.

Child-to-Child: Mentally handicapped girls care for multiply disabled children.

The participants in the course were deeply concerned about the inadequate care that the disabled children at the hostel were receiving. They realized that the women at the hostel were far too overworked. "The hostel desperately needed more staff, more help! Children are starving because they don't have enough attendants to feed them! But what can be done? In the present economic climate, the government consistently cuts back on budgets for public services, even as the need grows. What to do?"

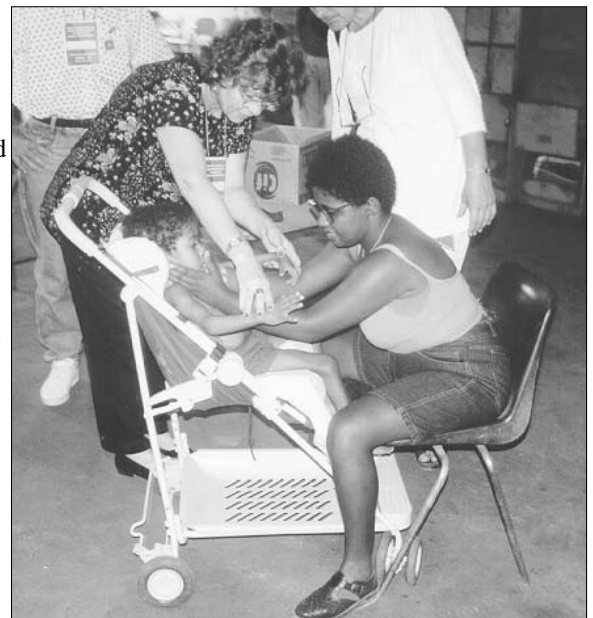
Then an idea came for a possible solution. Next to the government hostel for multiply disabled children is another hostel for orphaned and abandoned mentally handicapped girls. Indeed, both hostels are part of the same institution, although managed separately. The girls are cared for in small group homes, and are taught to be as self sufficient as possible. Some of them read and write and attend normal school (a big step forward). They are also taught work skills. But finding employment is difficult. And because many of the girls have no place to go as they get older, they continue living in the hostel with little direction or purpose in their lives.

A solution to the dilemma of both hostels was evident. One hostel was desperately in need of more staff to help hold, hug, and feed the multiply disabled children.

The other hostel had a group of mentally handicapped girls who needed activities to give them a sense of worth. The 2 hostels were separated only by a high wire gate. Why not unlock it? Why not invite the older, more capable mentally handicapped girls to help care for the severely disabled children. The latter needed mothering; the girls longed to be maternal. Much of the care needed for the multiply disabled children required more time and patience than skill. They needed holding, hugging, loving, simple exercises, bathing, and above all, food. Wasn't this the kind of meaningful occupation that many of these mentally slow girls were longing for?

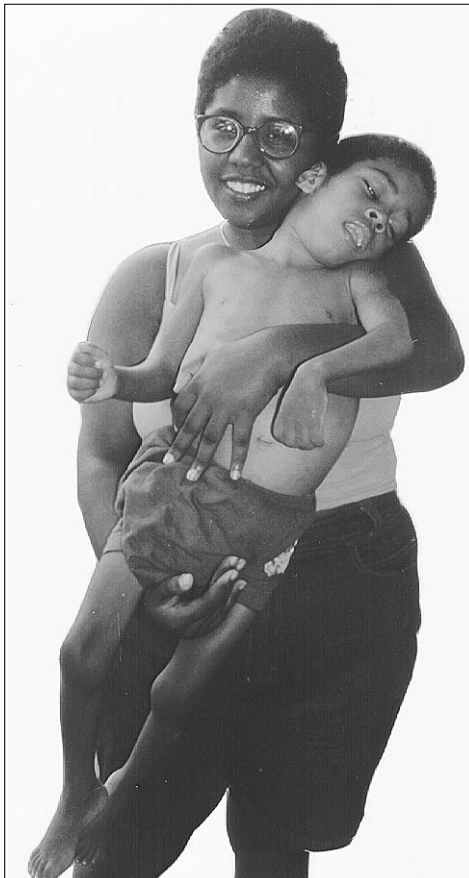
Following up on this suggestion, on the second day of the workshop the coordinators of the government hostel brought one of the older, more able girls along with the 6 children. The girl, Maria, was excited and eager to help. One of the course participants, the mother of a dis-

abled child herself, helped show Maria how to hold and handle a younger girl who had cerebral palsy and almost no body control. Maria soon learned how to position the younger child in her new special seat. Then another participant, a physiotherapist, showed Maria how to help the child begin to develop head control by holding her upright by the shoulders and gently supporting the back of her head with her hands.



Course participants teach Maria, who is mentally handicapped, to help care for a profoundly disabled child. Here Maria learns simple activities to help the child gain better head control.

Follow-up. The most important outcome of the workshop, perhaps, was not the equipment made, but the prospects for improving the care for the disabled children in the government institution. Several of the participants who lived in Recife offered to make regular visits to the hostel to trouble-shoot problems and to try to find solutions. An exceptional physiotherapist agreed to work with the staff of the hostel to continue teaching Maria and other mentally handicapped girls how to feed, provide exercise, and care for the younger children. Another course participant, Father Eduardo Figueroa, also agreed to counsel, assist, and if possible, find additional funding for the hostel. Father Eduardo runs a family home for 50 abandoned children, 9 of whom are disabled. Although some of Father Eduardo's children are extensively and multiply disabled (one is paralyzed, deaf, and blind), all are well fed and very much loved and cared for. Most importantly, the older and more able children take pleasure and pride in caring for and teaching the younger ones. It is Child-to-Child at its best. Father Eduardo's assistance at the hostel will be an enormous help.



Everyone agreed that one of the greatest achievements of the course was the group's realization that a mentally handicapped girl like Maria could play a vital role in the care and rehabilitation of a profoundly disabled child.

Final evaluation. The course for multipliers of CBR finished with an evaluation by the participants. All felt that they had learned a lot. Some persons' remarks were moving.

As one rehabilitation center coordinator spoke of her experience with Enrique, she burst into tears. "I didn't know there were children like this in Brazil," she lamented. "So starved, so neglected, and in our own official institutions. I'll never forget the tears in little Enrique's eyes when he so much wanted to tell us something, and could not." She wiped her eyes. "But somehow I guess he told us a lot."

At the end of the evaluation, a blind participant stood up and said, "We have learned something about Community-Based Rehabilitation. But we have learned a lot more. We have learned that what disabled activist, Joshua Malinga, said is true: **'It is society that needs to be rehabilitated.'** Brazil is a wealthy country. We have enough resources to meet everyone's needs, to provide a roof and food and health care for all. Yet there are 5 million homeless kids on the streets. Not far from this 5-star hotel in which we have been meeting there are famished, disabled beggars picking through garbage heaps. We who are disabled, and we who work for and with disabled people, need to stand up for the rights of all hungry and disadvantaged people, to fight for a society where people are more equal, in which no one grows fat while others starve. It is our society that needs to be rehabilitated. This is what should be meant by Community-Based Rehabilitation." Everyone stood up and applauded. The course was over.

Announcing a New Video and Guidebook ***Child-to-Child: at the roots of health***



Nominated "Best Community Health Video of 1996" by the American Medical Association, *Child-to-Child: at the roots of health* takes viewers to Mexico where Child-to-Child has developed into a fun-filled process that empowers children to identify the problems affecting their health and well-being. Utilizing Child-to-Child activities, children analyze the root causes of poor health and take collective action to protect the health and well-being of themselves, their families and their communities.

Activities demonstrated in the 17 minute video address dehydration, diarrheal disease, measles, pollution,

and disability. An 80 page companion guidebook details Child-to-Child as practiced in Mexico. The guidebook also provides a case study in Chicago demonstrating its versatility with examples dealing with different types of problems, such as drugs, gangs and alcohol abuse.

For more information, or to order the video and guidebook, please contact Peterson Productions, PO Box 617, Tiburon, CA 94920 USA, FAX 415-435-5321, or Phone 415-435-0332. Mention Newsletter from the Sierra Madre and receive a 10 percent discount.



A FORTHCOMING BOOK BY DAVID WERNER, HEALTHWRIGHTS, AND PROJIMO:

NOTHING ABOUT US WITHOUT US

DEVELOPING INNOVATIVE TECHNOLOGIES
FOR, BY, AND WITH DISABLED PERSONS



A companion to DISABLED VILLAGE CHILDREN. This exciting new book is scheduled for release in early 1997 and will be a companion to David Werner's previous book, *Disabled Village Children*, which has become one of the most widely used Community-Based Rehabilitation guide-books worldwide.

50 stories. Unlike *Disabled Village Children*, however, *Nothing About Us Without Us* is more of a storybook than a guidebook. Its purpose is not merely to instruct, but to transform, to awaken readers—especially disabled persons and those working with them—to new and exciting possibilities. The book consists of 50 true stories, from Project PROJIMO (a world-renowned CBR program in western Mexico) and around the world, which stress one important theme:

Assistive devices and techniques for disabled persons tend to work better and be more empowering when the disabled user takes the lead- and when he or she is involved as a partner and equal in the problem-solving process.

Although this is a book about innovating assistive devices and user-centered approaches to meeting needs, it differs from other manuals in that **it puts the person and the process before the product.** With the help of **hundreds of line drawings and photos**, the book covers a wide range of innovative equipment that can be made with local materials at the village or community level. In presenting each innovation, it places emphasis not so much on the end-product (however important) as on the **collaborative process of discovery.**

User-centered. Nearly every example in this book, starts by looking at a disabled individual—often a child. With that person central to the problem-solving process, we explore his or her unique combination of wishes and needs. We describe the cooperative, trial-and-error methods used in designing solutions to meet those needs. The problem-solving process is open-ended and ongoing. Sometimes it entails learning new skills, sometimes it involves modification of environment, and sometimes it leads to the invention, adaptation, or elimination of an assistive device. **Creative adventure is key.**

This new book is organized into an introduction and 4 sections:

INTRO: DISABLED PERSONS AS LEADERS IN THE PROBLEM-SOLVING PROCESS

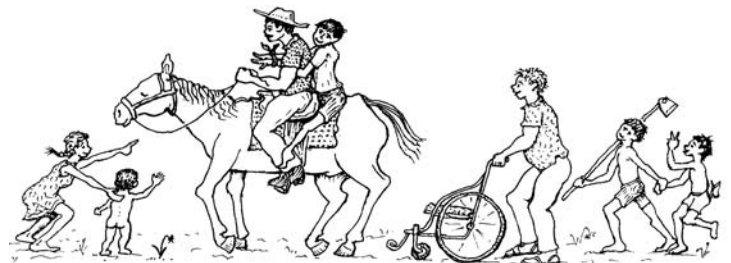
PART 1: THE PURPOSE OF SPECIAL SEATING: FREEDOM AND DEVELOPMENT, NOT CONFINEMENT

PART 2: CREATIVE SOLUTIONS TO PERSONAL AND SITUATIONAL NEEDS

PART 3: FREEDOM ON WHEELS: DESIGNING MOBILITY AIDS TO MEET INDIVIDUAL NEEDS

PART 4: INNOVATIVE METHODS AND APPROACHES: PEOPLE HELPING AND LEARNING FROM EACH OTHER AS EQUALS

PART 5: CHILD-TO-CHILD ACTIVITIES THAT INCLUDE AND EMPOWER DISABLED CHILDREN



Nothing About Us Without Us. 320 pages. Hundreds of photos and drawings. Pre-publication price: \$12.00 plus postage.

If interested in obtaining a copy when available in 1997, contact:

HealthWrights
964 Hamilton Avenue
Palo Alto, CA 94301, USA
Fax: 415 325-1080; Tel: 415 325-7500
email: healthwrights@igc.org

**The following are samples from three chapters from
NOTHING ABOUT US WITHOUT US:
Developing Innovative Technologies For, By and With Disabled Persons**

Using Spasticity for Independent Living

Through experimentation Julio has learned to use his spasticity to be more self-reliant, despite his paralyzed hand and weak arms. He has also developed strong shoulder muscles to help compensate for his weak arms.



Julio uses the spastic straightening of his knees to transfer from wheelchair to bed.



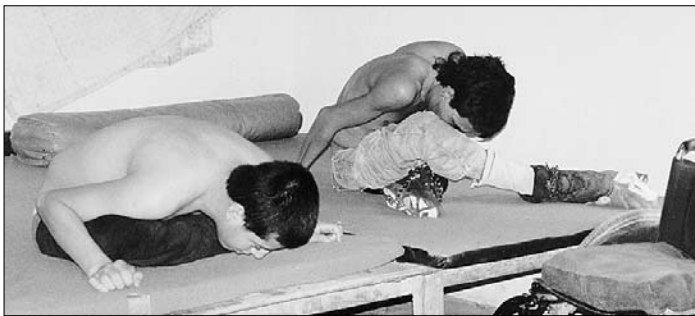
Here he shows how to use his spasticity to straighten his knee.



And now he manages to 'break the spasticity' and bend the knee.

Julio Teaches Daily Living Skills to Another Quadriplegic Youth

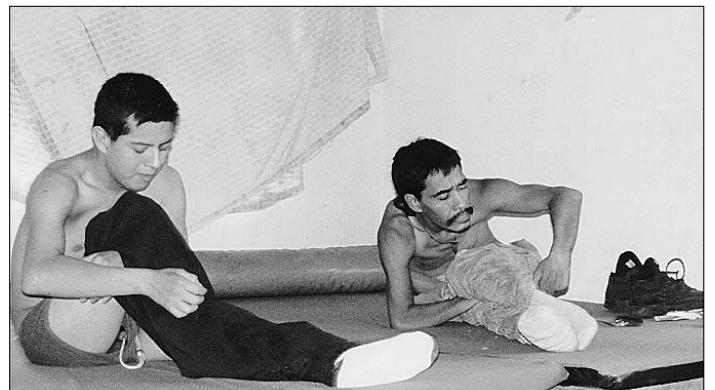
Romeo was working as an 'illegal alien' in the USA to send money to his ailing mother back home. He became quadriplegic in a car accident. After 3 months in a hospital he was sent back to Mexico. On his arrival at PROJIMO, Julio quickly became his friend, role model and tutor. In California a nurse had given Romeo a 'transfer board' for moving from wheelchair to bed. But within 2 days at PROJIMO, Julio taught him to move to and from his wheelchair without help and without a transfer board. Then Romeo followed Julio's example.



Julio also taught Romeo to dress himself. First came exercises for bending forward.



Next, Julio demonstrated different dressing techniques while Romeo watched.



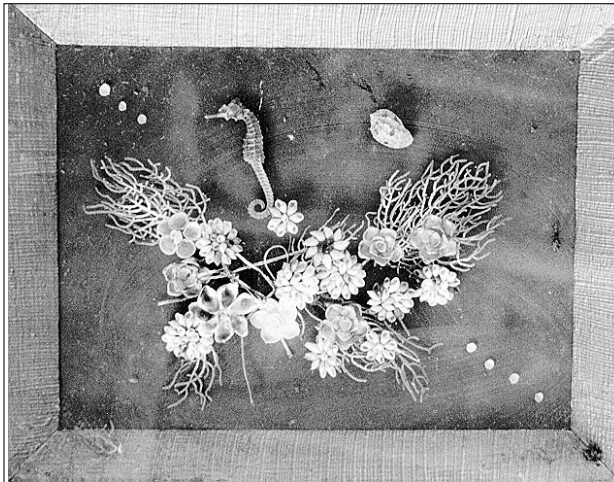
Having a capable person with the same disability as a teacher made learning easier. Both Julio and Romeo benefitted greatly.

Four children with Muscular Dystrophy Lead a Program for Disabled Children

The Peraza family lives in a poor neighborhood of Mazatlan city. When the parents realized that four of their children had a disabling condition, they were determined to do everything possible for them. At that time in Mazatlan it was impossible to get significantly disabled children into the public schools. So they created their own school. With the help of an exceptional social worker, Teresa Paez, the Perazas met with families of other disabled children in the community and determined to start their own education and rehabilitation program for their children. They called themselves *Los Pargos*, the name of a local fish which the elite consider inferior.



Los Pargos was organized as a cooperative, of which the disabled children and their parents were participating members. Most of the families were quite poor. To raise money for school supplies and transportation, the families made colorful trinkets to sell. Outstanding among these were artificial flowers and ornaments, made mostly out of fish scales. Parents and children would go on 'work picnics' to the seashore, where fishermen cleaned fish. They collected sackfuls of fish scales, washed and sun dried them, stained them different colors, and glued them together into delicate flowers and bouquets.



A framed design with flowers made with fish scales and sea shells, made by the Pargos and their parents.

All four of the Peraza siblings became gifted artists and craftspersons. But the most outstanding was Sósimo.

Like the other *Pargitos*, Sósimo had a fascination with the ocean and its creatures. One of his most haunting paintings is a portrait of a woman in the bottom of the ocean.



This photo of Sósimo in his late teens reflects his combination of artistic ability, self-determination, and his radiant joy in the creative process. I wish all children with muscular dystrophy, and their parents, could have a chance to know and learn from Sósimo and his family.

After Sósimo had died, his sister Dinora told me he had painted it "because when people die they go to the bottom of the ocean and that is what makes the waves."

Eventually, over a period of several years, one after the other of the three Peraza brothers died from pulmonary complications. (Now only their sister, Dinora, is alive).

It was amazing what these four youth with muscular dystrophy managed to accomplish, and the pride and joy they took in doing it while their physical condition gradually deteriorated. For all their creativity and problem-solving skills, they could not halt the progress of the disease. But the dignity, caring, and leadership skills they developed and shared with their peers lives on.



Appropriate Paper-based Technology (APT)

Most of the special seats described in this book have been made at fairly low cost with wood or plywood. But for many families even local wood is too expensive, or hard to obtain. For this reason, in Zimbabwe, Africa, many years ago an elderly man named Bevill Packer began to make special seating and other assistive devices out of waste paper and cardboard. In this Appropriate Paper-based Technology, layers of paper and/or cardboard are glued together with paste made from flour and water. Paste can even be made from leftover 'sadza,' a flour porridge widely used as a weaning food. When well made, these paper-based seating aids and other devices can be unbelievably strong.

Apart from **low-cost** (in terms of materials), paper-based technology has other advantages:

- **Easy and fun to make.** Young children can take part in making the equipment. (However, considerable care with technique is needed for the results to be strong and durable.)
- **Very adaptable to personal needs.** Seat-backs and various supports can be molded to meet the needs of the individual child. Similarly, adjustments can be made, hollows scooped out, or protrusions (lumps) added where needed for added comfort, protection, or support.



This stool, made only of paper and cardboard, can support 3 people. (Photo from APT manual by Bevill Packer.)

- **Gentle touch.** Especially when the main structures are made of corrugated cardboard (as used in many 'thick wall' cardboard boxes) the resultant seat or device has a surface that is somewhat flexible. This provides a softer, more giving, more personal touch and is gentler where it comes in contact with knees, butt bones, and other bony areas. Thus it tends to be more comfortable and protective (against pressure sores) than wood, plastic, or metal.

Cruz is a 2 year old boy with a type of cerebral palsy that ranges between floppy (low muscle tone) and spastic (uncontrolled tightening of muscles). His mother loves him dearly and devotes a lot of time to helping him develop his body, mind, and spirit to their best potential. Cruz's brothers and sisters also enjoy playing with him, talking to him, and helping him with activities. Thanks to this loving family effort, Cruz has gained fairly good head control, and with difficulty manages to open his hands to wave hello and goodbye. He is learning to sit with the help of sandbags across his folded knees and against his hips. He also tries very hard to speak. Although his words are hard to understand, his family has learned to interpret them, and encourages him to speak as much as possible. The boy thrives on all the hugging, handling, and encouragement he receives.

A wooden seat the child hated. Cruz's mother brought the boy to PROJIMO from a village about 15 miles away. In a dynamic interchange of ideas and experience, the rehabilitation workers learned as many practical developmental activities from his mother as they were able to teach her. It was agreed that Cruz might benefit from a special seat. Juan designed and built a handsome plywood seat for him, complete with a removable backrest so that, when the backrest was removed, Cruz would need to use his back and trunk muscles to sit upright.

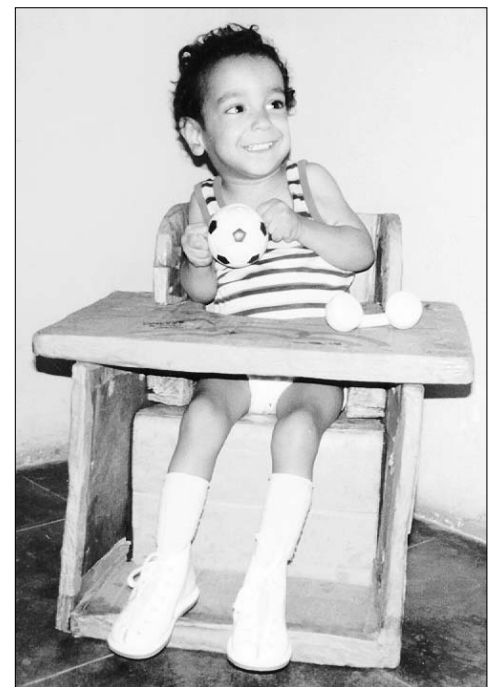
But for some reason Cruz hated his wooden seat. Though usually cheerful, whenever he was placed in the seat, he began to scream and wail. His mother was sure he would get used to it, but after two months he still refused to accept it.

A cardboard seat he liked. Because at this time PROJIMO was experimenting with paper-based technology, they tried sitting Cruz in an uncompleted seat made of lami-

nated corrugated cardboard. To everyone's amazement, he was all laughs and smiles. His mother was amazed at the difference.



We are not sure why Cruz—who had such a strong dislike for the plywood seat—took an instant liking to the cardboard one. The positioning and support provided by each was much the same. We suspect that the cardboard seat—with its thick, rounded, relatively soft, yielding structures—was somehow friendlier and more similar to human touch. By contrast, the plywood seat, even with its cushioned lining, was more rigid and unyielding; despite the smiling rabbits painted on its sides, it was not as child-friendly.



A cardboard seat was built to meet Cruz's particular needs. At the front of the seat a removable post, or pommel, was placed to keep the boy from slipping forward. A large table top fit low around the boy's waist, to help stabilize his lower trunk. A removable, U-shaped hip support fit into the seat, to help stabilize his hips and to hold him slightly forward from the seat back. That way, when he chose, he could sit upright without leaning against the seat back. (The idea for this U-shaped hip support came from watching Cruz's mother place sand bags around his hips to help him sit upright.)



The seat was formed by large sheets of cardboard that were bent to form the sides and back. After temporarily gluing they were temporarily sewed with string to press them together as the paste dried.

All the parts of the seat—including the table top, pommel, and U-shaped hip support—were made by **laminating (pasting together) layers of corrugated cardboard** cut from old cartons. On trial, Cruz sat fairly well in the seat. But there were some problems, which required modifications in the seat:

1. When Cruz was excited, his legs stiffened and his tense body pushed backward. So a **removable ankle bar** was added to keep his feet on the footrest. The bar was made of cardboard reinforced by a flat metal rod, bent to help position his feet. A **removable foot-separator** of layered cardboard was added to help him position his feet well.
2. Although the U-shaped hip-support at times seemed to help Cruz sit upright often he would slump or push back against the seat back. Therefore, a **low-back support** of layered cardboard was added, which could be removed once he gained better hip and back control.



Children in the village helped to build the cardboard seat.



A Cardboard Standing-Board for Cruz

Cruz's mother, brothers, and sister often held the boy in a standing position, and Cruz did his best. At first his legs would stiffen spastically in a tip-toe position. But if held quietly for a few moments the spastic muscles would gradually relax and his feet would flatten on the ground. Cruz's mother had brought him new, high-top shoes, which seemed to help him position his feet better.

The PROJIMO team felt Cruz might be ready for a standing-board. As for his special seat, they decided to use corrugated cardboard as the primary structure. The cardboard was reinforced with wooden struts and had a wooden base-board.

On a preliminary trial of the standing board, Cruz stood fairly well on it. His feet rested flat on the base-board and were held apart by the foot-holes in the vertical frame. The boy seemed delighted with being able to stand 'independently.'



← However, the boy's knees angled inwardly as he stood. He needed something that would hold his legs straight and apart. So a **leg-separator** was made by reshaping and gluing together two cardboard boxes to form a long, thin triangle. →

A big advantage to a standing frame made of cardboard is its smooth, soft surface and its capacity to bend or sink in slightly under pressure. The cardboard therefore provides more gentle support for bony areas such as Cruz's knees.

In conclusion, PROJIMO's early trials with cardboard assistive devices show great promise. The PROJIMO team still needs to improve its technology, to create smoother, cleaner products, but the results are remarkably functional. Cardboard has a number of advantages over other materials: especially its low cost and the ease with which structures can be modified and adapted to meet individual and changing needs.



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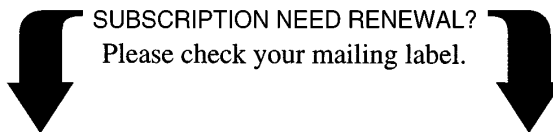
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December 1996

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This issue of
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