

# Newsletter from the Sierra Madre #52

## December, 2004



### **PROJIMO Community Based Rehabilitation Program**

run by and for disabled villagers in western Mexico (Coyotitan)

### **HEALTHWRIGHTS**

Workgroup for People's Health and Rights

### **PROJIMO Skills Training and Work Program**

run by disabled youth in rural Mexico (Duranguito)

The previous NL (July, 2004) looked at the ways Cuba—despite the prolonged US embargo—has succeeded in achieving a level of health equal to that of the United States at 1/20 per capita income, through a model of development that strives to be both equitable and ecologically sustainable. This issue looks at a pioneering effort to meet the needs of Cuba's disabled people through a community based initiative led by disabled persons' organizations with multisectoral government support.

## Cuba's Pilot Project in Community Based Rehabilitation

In May, 2004, Handicap International Belgium (HIB) invited David Werner to conduct an external evaluation of Cuba's first experiment in Community Based Rehabilitation (CBR). The year before he had evaluated a CBR program for HIB in Cartagena Colombia. The Cuban project's new director, Ana Calvo—who accompanied David in Cartagena—urged him to evaluate the pilot program in Cuba. Eager to get back to Cuba, David jumped at the chance. Here he describes both the strengths and weaknesses of the program.

The idea behind CBR is to empower disabled persons, families, and communities with the knowledge and skills to meet many rehabilitation needs in their own homes and communities, at low cost using local resources. CBR is seen as a complement, not a substitute, for institutional services. Indeed, the success of CBR often depends on the quality and extent of the backup professional services. Another objective of CBR is to shift from the "therapeutic model" of institutionalized rehab with a strong biomedical focus to more of a "social model" where individual therapeutic measures are balanced with social action. The goal is inclusion and equal opportunities (normal schooling, jobs, etc.) within society.

### **Off to a slow start**

Several years ago, HIB approached the Cuban Public Health Ministry (MINSAP) with the proposal to start a

pilot CBR project. Convincing the Ministry of the need for CBR was not easy, as Cuba prides itself on its outreach of professional services even into remote communities. It saw CBR as a second-best alternative for countries unwilling or unable to invest in professional services for poor communities.

But the timing was right. In the last few years—in part due to the constraints of the embargo—Cuba has been rediscovering the importance of giving more responsibility to families and communities in meeting their own needs. They see this as a way of complementing professional services, not replacing them. A decision was reached to start a CBR pilot project in mid-2001. But the gears of centrally controlled decision-making turned slowly. The project finally began in January 2002, six months behind schedule.

### **Serving the most remote areas first**

The pilot project was started in the Province of Granma, named after the small boat that Fidel, Ché and their small band of revolutionaries sailed from Tampico, Mexico on their way to liberate Cuba from the US-supported dictatorship of Fulgencio Batista. In Granma two municipalities were chosen for the CBR Project: Guisa and Bartolomé Maso. These were chosen because they extended into the far reaches of the Sierra Maestra, home to some of the poorest and least accessible communities on the island.

### **Key role of disabled persons' organizations**

One outstanding feature of the Cuban CBR Project is the central role of disabled persons in management, leadership, and to some extent, service provision. Too often CBR programs are run and managed by non-disabled persons. Project PROJIMO in Mexico is a notable exception.

Three national associations in Cuba are run for and mostly by disabled persons. These represent blind, deaf, and physically disabled persons. In the CBR initiative, the core groups at the national, provincial, and municipal levels include representatives from 6 organizations: the Ministry of Public Health (MINSAP), the Ministry of Education (MINED), the Ministry of Work and Social Services (MTSS), and the three Associations of Disabled Persons. I was delighted to see representatives from these 3 disability associations working alongside the ministry reps and playing a key role in the planning, training, and community-level services of the CBR Project.



Outside the humble "Headquarters" of the CBR program in Bartolomé Maso is a bust of the revolutionary Cuban poet, José Martí, with a tablet that reads: "The physical defects of people matter little if from their hearts spring noble and just ideas."

## “Activistas”

A second outstanding feature of the Cuban CBR project is the highly dedicated role and perseverance of the community-level front-line volunteers. The key actors in the CBR program at the home and community level are volunteers with basic training who are appropriately called "Activistas." I was amazed to see the eagerness, energy and continuity with which these community rehabilitation Activistas worked. Many put in up to 20 hours a week in their CBR work, which includes home visits to disabled persons, as well as "sensibilización" (awareness raising) activities in the villages.

**Home visits**—a key part of CBR—are no small task in the Sierra Maestra. Some disabled persons live at the end of precarious footpaths deep in the wilderness. One Activista, Wilberto, walks twice a month 20 kilometers each way to visit a man who had a compound fracture of his leg. The man had received comprehensive medical care. Carried on a stretcher 20 km. to the *policlínico* in the municipal seat of Bartolomé Maso, he had received free surgery and the early stages of rehabilitation. But he desperately wanted to get home to his family, and left early. The long distance for his return rehab appointments at the polyclinic made continuity difficult. He developed muscle contractures and two years after his accident had still not regained his ability to walk—until Wilberto began to visit him. Wilberto instructed the man and his family in home exercises to restore range-of-motion and leg strength. Today this man no longer sends a child to look for his mule at pasture. He goes himself.



In rural areas many homes are made of adobe (mud bricks) and roofed with a thatch of palm leaves.

Like so many of the other rehab Activistas I talked with in Cuba, Wilberto welcomes the challenge of his volunteer work. He feels deep satisfaction in the benefit he provides others, and enjoys people's appreciation of his efforts. Here, Cuba clearly has an advantage over many CBR programs I've seen, including the one in Cartagena, where the participation of the CBR volunteers in poor communities tends to be far less sanguine. The same goodwill exists. Most would like to do more to help disabled persons and their families. But the time they can devote to their volunteer work is so little they never receive enough experience to develop the sound judgment and problem-solving skills needed to provide competent technical advice and assistance. The hardship they face just to feed and care for their families are such that they simply can't find the necessary time for their CBR activities. Quality of service suffers accordingly. The harsh constraints of poverty on volunteers is, in my opinion, the Achilles heel of most CBR programs. And the resulting inadequacy of technical services helps explain the widespread skepticism about CBR—including that encountered initially in Cuba.

### What makes CBR more effective in Cuba

Cuba is different. While widespread poverty exists, it is neither as extreme nor as incapacitating as in many countries. One way or another, everyone's basic needs are met. People don't have to struggle to survive. They don't worry about paying the medical bill when their child gets sick, or about tuition if a son or daughter wants to continue their studies. Because people's basic needs are met, those in poor communities have both the time and the community support to help one another, and many love doing so. This gives real potential for high quality CBR services in Cuba.



Wilberto (on left) walks 20 km. each way round trip into the mountains every 2 weeks to visit this man, whom he has helped learn to walk again after his leg was injured in an accident two years before.

### Multisectoral government involvement

A third outstanding feature of the Cuban CBR project—again distinguishing it from others—is the strong active involvement of an entire network of official health and welfare services, especially at the community level. I was impressed how well the representatives from different service sectors cooperate with their disabled colleagues in the Associations of Disabled Persons. This interaction is aided by the fact that many Activistas, some disabled themselves, hold positions in government services at the community level: as teachers, nurses, special educators, family counselors, and members of women's, youth or farmworkers' associations. This gives them close ties with a range of public services agencies, which they can call for backup or referral when needed. Consequently, the multisectoral support system, which is often a weak point in many CBR programs, works refreshingly well in Cuba.



Trainers and instructors travel deep into the Sierra Maestra to provide backup for the Activistas.

## Sensibilización

As with many CBR programs, the social aspects of the pilot project in Cuba tend to be the strongest, while the technical or therapeutic aspects are weaker. The Cuban Project conducts many innovative "*sensibilización*" activities in the villages to raise people's awareness about disability. The emphasis is on fuller inclusion and equal opportunities. I was delighted to see that many of the colorful posters displayed in schools and public buildings are based on illustrations from my books.



Many of the disability awareness-raising posters are adapted from the books that grew out of PROJIMO in Mexico, such as this one that says "look at my strengths, not my weaknesses."

## Traveling puppet show

In Victorino, a village in Guisa, I had the privilege of watching the first presentation of a disability awareness-raising puppet show performed by a traveling village theater troupe sponsored by the CBR Project (mainly HIB). The lively skit—titled "El Tesoro Laboral" (roughly translated as The Treasure of Manual Labor) portrays an amputee named Juan who is at first overprotected by his aging father, until the boy takes the lead in making the farm produce. To see this puppet show, school children came from miles around, some on foot from high in the mountains. The skit kept them spellbound.



For scenes that take place further from the family house in the puppet show, smaller puppets are used.

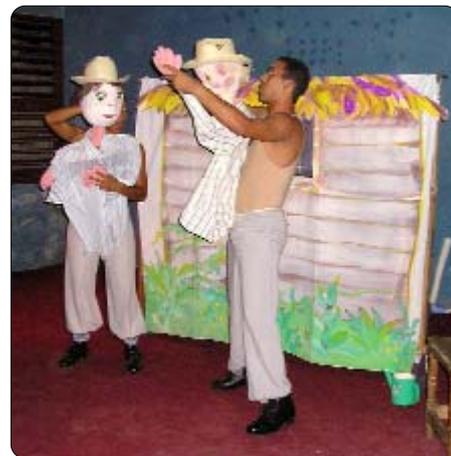
## Top-down "participatory" discussion

Following the show was a "participatory discussion" that was intended to give the children the chance to express what they'd learned. However, the kids were hesitant to speak, even when urged. So a man stood up and delivered a long speech on what the children should have learned. Then another did the same. Inside the community "Television Hall" it was hot as hell. A hundred sweaty kids sat obediently, yawning and fidgeting; it was much like school anywhere. The kids said little.

I was able to discover what some of the children had learned from the *sensibilización* activities by talking with a few privately at snack time. They said they'd learned they should "provide care" for disabled children and "assist them." But nothing about regarding disabled children as friends or playmates, or including them in their games. It struck me that Cuba's effort to evolve from a top-down dependency-creating system to a more participatory approach to meeting needs still has a long way to go.

## School kids learn sign language!

I then witnessed something truly inspiring! It was the schoolchildren's turn to present. After dutifully sitting through the typical routine of poems and songs and recitals about "accepting people with disability" and "everyone loving each other," something astounding happened. A group of young children who had hiked down the mountain from a remote village called Los Gigantes stood before the crowd. In the front row of seats sat a line of deaf persons, trying hard not to fall asleep. Deafness is common in the small mountain villages, due to inbreeding. In some cases whole families are deaf. To include deaf children, the schoolteacher from Los Gigantes, who was also a CBR Activista, had taken an innovative approach. Rather than simply teaching her class *about* disability, she had taught them the rudiments of sign language. Now, in the meeting hall, one child after another began to "talk" in sign to the deaf folks. Coming to life, the deaf people began eagerly signing back to the students. It was an inspiring breakthrough for everyone.



A practice session of a puppet show about a disabled boy who makes good, put on by a troupe—sponsored by the CBR project—that plans to take the show from village to village in the Sierra Maestra. The boy, Juan (left) has an amputated arm.

## Interest in Child-to-Child

Following this experience, I discussed with the CBR team the Child-to-Child program, which we have actively developed in Mexican villages. In Cuba, where mainstreaming is still relatively new, innovative ideas were forthcoming for bringing deaf children into the normal schools. All disabled children have the opportunity for schooling, gauged to their potential. But the focus is still on separate special schools, with boarding facilities for those who live far away. Special educators I spoke with endorse the "separate but equal" approach, and feel that disabled children—especially deaf ones—would be too isolated in the normal classroom.



After the puppet show a group of school children from the remote village of Gigantes, whose teacher is a CBR Activista, communicated with deaf persons in sign language.



This young man, who has a paralyzed leg, gives a "rap" performance at the CBR headquarters in Bartolomé Maso. There they accompany their speech and song with sign language so as to include persons who are deaf.

However, many possibilities for Child-to-Child exist. Cuba has a program called "Jornadas de Interés." Schoolchildren are given an opportunity to apprentice with adults working in the vocation they aspire to: be it medicine, nursing, agronomy, police work, teaching, automotive mechanics, or carpentry. So why not for the deaf? Cuban children are exposed to sign language on television programs, many of which include a corner image of someone signing. If Cuban schools were to include a brief introduction to sign language, as in *Los Gigantes*, those children who show interest could apprentice with an interpreter. They could then serve as "junior interpreters" for deaf children in the classroom—as well as teach signing to the other children.



This young man, who has congenital deformities of both upper limbs and one leg, works delivering cooked meals every day to more than 20 disabled persons who are not able to come to the comedor.

What excited me in these discussions with the CBR team and government representatives was their eagerness to explore new ideas. In Cuba there were many other innovative examples of "awareness raising." The best went beyond posters and skits to real-life examples of ways to include disabled people in meaningful community activities. An example:

**Meals on Wheels.** Most Cuban towns have special government-sponsored "comedores" or dining halls for disabled and elderly persons, which provide two free meals a day. For those who can't make it to these dining halls there is "meals on wheels" delivery; usually *bicycle* wheels. In one village we visited, the person delivering meals to nearly 30 disabled persons is himself physically disabled. Born with deformed arms and hands, and one deformed leg, this young man nevertheless rides skillfully through the village, relaying hot meals in batches of 8 "cantinas" (stacks of metal dishes), which he carries in a big basket on his bike.

It seems to me that one disabled person bicycling through the streets, proudly providing this kind of public service, makes more impact than a thousand awareness raising pictures.

#### **Strengths and weaknesses of CBR home visits:**

While the social and integrative aspects of the CBR Project had many outstanding features, the therapeutic side was more problematic. Of the several home visits I attended to observe how Activistas worked with disabled persons and their families, about half were carried out capably. For the other half, the activities or advice revealed serious weaknesses, most fairly easily avoidable.

Note: I should point out that the weaknesses I observed in the technical/therapeutic area are characteristic of most CBR programs I have visited in various countries. But given the many strengths and possibilities in the Cuban program, I expected better.

**The deficiencies in the therapeutic services and advice** appear to have three underlying causes:

- **First**, is the *brevity of the Activistas' initial training*: just three weeks. This

is far too short to adequately cover the breadth of activities they perform.

- **Second**, is the *inadequate follow-up and continued training* of Activistas and their supervisors.
- **The third** has to do with the *methods of instruction, shortage of participatory problem-solving skills, and job expectations that focus on the quantity more than quality of services rendered*.

Here are some examples of home visits I observed that demonstrate both strengths and weaknesses.

#### **Home visit #1: Success? Failure? Both?**

Salvador is presented as one of the success stories of the CBR project. A frail, hunched man in his mid-60s, he had been unable to walk for two years. With the help of the local CBR Activista, he learned to walk again—more or less. Salvador's progress is dramatized in an impressive new video documentary of the CBR project, which we watched in a local school.



Inside the workshop for the deaf in Bartolomé Maso, the "No to Terrorism" sign refers not so much to acts by Al Qaeda, as to acts by the US government.

Salvador lives with his aging wife in a modest house in the village of Monjará. For several years he has had a degenerative condition, which the local Activista, Maritza, for lack of a better diagnosis, labeled "*arthrosis*." Unable to walk, Salvador spent his days slumped in a chair, doing nothing. He had become very despondent. Doctors prescribed various medicines and a psychologist made periodic house calls. But nothing helped much.

Then Maritza, an energetic and very committed woman in her forties, began to visit the house 3 times a week. She involved Salvador's wife in a home-based exercise program. She also recruited a local carpenter to make low-cost assistive devices. These included wooden parallel bars and a vertical ladder so that the man could pull himself to standing. Salvador gradually succeeded in taking a few steps independently, though his knees were still quite bent, making him tire quickly.



Salvador is an elderly man with a rheumatic condition, who had been unable to walk for years. With the help of the Activista Maritza, he began to walk again for short distances, but in a crouched position with his knees bent.

With all this attention Salvador's mood improved considerably. His wife took pride in helping him with his exercises, and the two seemed more understanding of each other.

Concerned with the social part of his rehabilitation, Maritza arranged for a variety of assistive services and benefits. So Salvador's wife wouldn't have to leave her frail husband alone for long, Maritza convinced the manager of the local subsidized food stamp store to attend her quickly. Rather than having to wait her turn in the long line, Salvador's wife could come up front. That way she could get back home sooner.

Maritza also arranged for Salvador to attend public events. A bicycle rickshaw driver takes him to watch Saturday baseball games (which he loves). She coaxed other lonely elderly men and blind persons in the neighborhood to come play dominos with Salvador. That proved good for everyone.

From what I was told, Salvador's rehab appeared to be a great success. And in some ways it was. He recovered his ability to stand and began to walk. His spirit improved. He began to participate in community events. He even became a "movie star," appearing in the project's educational video.



Hoping to help Salvador walk more upright Maritza demonstrates the "range-of-motion" exercises she uses to straighten his knees. However, his knees straighten well. The difficulty that caused him to walk with bent knees turned out to be flexion contractures of the hip joints.

However, there is a down side to his story. Salvador's rehabilitation remains far from complete. His potential for walking better was largely unmet. He walks in a half-crouched position with his knees still quite bent. He therefore tires quickly and after a few steps has to sit. Hoping for further improvement, Maritza continues with the same range-of-motion exercises. But no further improvement is apparent.

Maritza showed us the exercises. She explained they were to help straighten his knees. However, when Salvador lay down, his knees were much straighter than when he walked. Clearly his crouching position when walking wasn't caused by knee contractures. Could it be from flexion contractures of the hips? Mauricio (a physiotherapist from Colombia coordinating the HIB project) and I asked a series of thought-provoking questions encouraging the group of Activistas to figure out why Salvador still stood with bent knees. We showed them how to test for contractures in both his knees and hips. Then—when they had discovered that his crouched gait was due to tightness in his *hips*, not knees—we discussed exercises and positioning that might help to straighten his hips.



In addition to his physical rehabilitation, since Salvador was very depressed, Maritza arranged for neighbors to come visit and play dominos with him.

It was disturbing to witness one of the CBR instructors demonstrate, rather authoritatively, exercises that were entirely inappropriate.



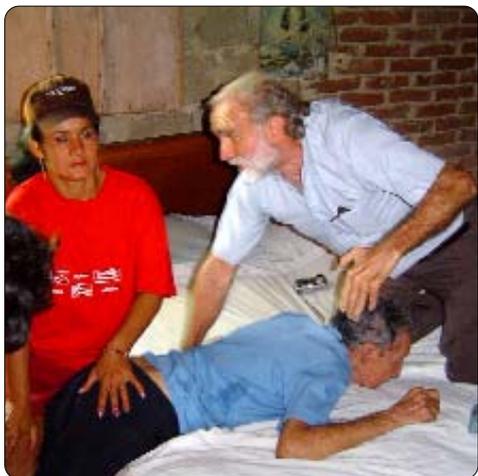
To learn a good exercise for straightening Salvador's hip contractures, Maritza first practiced on a willing boy.

Notwithstanding, I was impressed with the analytic skills and teaching ability of Mauricio, the HIB coordinator. Observing the inappropriateness of the exercises for the problem at hand, Mauricio guided the Activistas (and their instructors) through what he called a "logical process" of problem solving. By asking practical questions, he helped them discover the cause of the underlying problem, why the knee exercises were unlikely to help, and to figure out which exercises and activities might work better.

Eventually, the group, with considerable prompting, did figure out more fitting alternatives. They learned simple hip-stretching exercises (illustrated in my books). They made plans to construct a standing frame to help Salvador slowly stretch his contracted hips. By better understanding the chain of cause and effect, they can work more rationally toward helping Salvador walk upright and tire less. Everyone learned a lot.

I left Salvador's home with mixed impressions. In many ways the local Activista had done an outstanding job, especially with social, psychological, and community support. Also, I was impressed with Mauricio's participatory approach to logic-based problem solving. *With a few more rehab experts and gifted educators like him to help the Activistas improve their analytic and problem solving skills, the quality of the therapeutic side of this CBR project could be greatly improved!*

But a fact remained: the Activistas—as well as some of their instructors and supervisors—lacked the know-how and problem-solving skills to help Salvador approach his potential. Inappropriate exercises were applied, and had not been spotted and corrected by the backup team. Still more worrisome was that I saw the pattern of shortcomings I observed with Salvador repeated at other home visits. While the project has many excellent features, certain shortcomings, especially in the technical area, urgently need to be dealt with.



Here David Werner instructs Maritza in the exercises to help straighten Salvador's hips.



The CBR program has three motorcycles with side cars, supplied by Handicap International Belgium. They are used for trainers and supervisors to visit the rural areas where the Activistas work.

**Home visit #2: A need to break out of the box.** Our next visit was to the home of Alicia, a plump 43-year-old woman with a problem the local Activistas described as "arthritis." Alicia walked with a cumbersome, dipping gait. She complained of pain in her hip and lower back, which had increased over the years. When she had to walk a lot during the day, the persistent pain kept her from sleeping.

We had the opportunity to watch how the local Activista worked with her "patient." This was her first visit to Alicia's home. Alicia lives on the 4th floor of a large low-income apartment complex. The first thing the Activista did was to give Alicia her routine "charla" (informative talk) on "arthritis and arthrosis" using lots of big, scientific terms. Then she started a series of range-of-motion exercises on Alicia's right leg.

Unfortunately, the whole session was a comedy of errors. First of all, the Activista began treatment before asking questions to discover the real problem. She jumped to conclusions: since Alicia walked with pain, the Activista decided on routine treatment for "arthritis." This was one of the pre-packaged topics she

was supposed to teach, and she had a handout flyer on it. With Alicia lying on a bed, she applied passive range-of-motion exercises to her affected leg, ankle, foot and toes. When we asked why she was doing this, she explained (erroneously) that these totally passive exercises were "to strengthen her muscles." Apart from providing the exercises, therapeutically, she did nothing.

I asked Alicia about her problem and how it began. It turned out she had a congenitally dislocated hip. Her right leg was 6 cm. shorter than the other. Worsening her pain was the climb up and down 4 flights of stairs to her flat.

Given this new information I asked all those present—Activistas and representatives of the CBR team at the municipal and provincial level—if they thought the exercises performed by the local Activista would help. Disturbingly, most said, "Yes."



An activist applies inappropriate exercises to the leg of a woman with a painful congenitally dislocated hip. Activists need to look for solutions other than therapy—that's what "integral rehabilitation" of CBR is supposed to be all about.

Again, gently and methodically, Mauricio stepped in, encouraging a "logical process" of cause-and-effect problem solving. He helped the local Activista reason through a sequence of important logical steps, starting with a 2-way dialogue to learn more about the problem. Then, he helped her understand that passive range-of-motion exercises won't help strengthen muscles; to become stronger, muscles must be used. Finally, before doing exercises to increase range-of-motion, one needs a reason for doing them. Mauricio and I asked the Activista to check the range of motion in Alicia's joints. All around, it was normal.

As for muscle strengthening exercises, Mauricio asked, does Alicia really need them? She lives on the 4th floor. No elevator. Every day she has to climb up and down with her dislocated hip.

However, Alicia is seriously overweight. What recommendations might be most helpful?

"Lose weight!"

Yes, and what else?

A discussion evolved in which the group drew together a list of measures that might be helpful. It was interesting that most of the suggestions were now "outside the box" of the routine therapy procedures that the Activistas had been taught. Possibilities included:

- An effort to lose weight (with helpful recommendations)
- An evaluation of how Alicia climbs the stairs. Might there be a way to reduce stress on the affected hip and back?
- Experimentation with an elevated sole on the shoe of the shorter leg. (When this was suggested, Alicia protested. An orthopedist had put a lift on her shoe years ago, but it had increased her pain. Why might that be? We asked the group to discuss possible explanations. Perhaps the lift was too high, given the chronic deformities. Might a shorter lift be helpful? Why not experiment with lifts of different thicknesses? To do this at low cost, layers of cardboard could be temporarily taped to the sole of her shoe—to find out what added height, if any, might be most helpful.)
- What about all those stairs Alicia has to climb? To avoid having to climb them so often, could neighbors perhaps help Alicia with her shopping? Perhaps a willing child volunteer would help carry Alicia's groceries up the stairs?
- And finally—why does a woman, with her dislocated hip, have to live on the 4th floor? Clearly, moving to the 1st floor would make the biggest difference for Alicia's long-term well-being. In most countries such a health-providing

reassignment of dwelling would be difficult. But in Cuba, with the close link between the CBR team and the cooperating network of service organizations, it could be possible. And it would fit into the broad range of activities the Activistas tend to take on.



With this hand-powered "bici-taxi" a disabled man gives a ride to a disabled woman. (She said she was not afraid of falling.)

### Need for logical problem-solving skills

This exploration of possible solutions was a good learning session for everyone. It became clear that if the CBR program is to achieve its goal of "integrated rehabilitation" at the community level, the training of Activistas (and their teachers and supervisors) needs to be more extensive. Equally important—a s Mauricio often emphasized—it needs to focus more on logical problem-solving skills.

Development of these skills—people's ability to think for themselves, to make their own observations and draw their own conclusions rather than just follow a routine of standing orders—is important not only for improving the quality

of CBR home visits. It is equally important for improving the quality of life in any society that aspires to full equality and opportunities for all. This is the goal of CBR. It is also the goal of the Cuban Revolution.

"This is why CBR as we envision it is so important for Cuba!" said an outspoken disabled leader from the Provincial CBR Team. He had the rebellious glow of Bob Marley, as well as the dreadlocks. He and I hit it off from the first. "CBR can, in its own equalizing way, help Cuba realize the dream of Ché and José Martí: the dream of a just and caring Society for All! But," he added, "We still have a long way to go."

### Making CBR more inclusive

As originally planned, the Cuban CBR Pilot Project caters to only three groups of disabled persons: the blind, deaf, and physically disabled. Why? These are the only groups represented by their own nationwide, government-approved Associations. Since these three Associations are the structure through which disabled persons play a central role in the CBR Project, it had been decided to focus on these 3 disabilities.



This young man, a Special Olympics athlete, has run international races. His racing wheelchair was made in the workshop of the Association of Physically Disabled Persons in Bayamo.

## What about mental retardation?

The largest and most marginalized (most voiceless) group of disabled persons in Cuba are those with mental retardation. Families of mentally handicapped children have no national association, therefore they have less say in the decisions that affect them, such as special schools vs. mainstreaming. Is this not an argument for including them in the CBR program? Many Activistas find themselves working with children who, in addition to their physical, visual or auditory deficit are also intellectually impaired. They expressed the need for more information and skills for working with these children.

Concluding the "Evaluation Seminar" I raised the question of whether families of mentally handicapped children should be included in the CBR program. By vote, the decision for inclusion was unanimous. As a disabled Activista pointed out, it doesn't seem right to exclude any group of disabled people, since our stated goal is inclusion of those in greatest need.

I discovered that in Manzanillo, a neighboring municipality in Granma Province, parents of mentally handicapped children have formed their own local Association. Reportedly, they do an outstanding job of peer counseling, advocacy, preparation of special education materials, and community awareness raising. The CBR team responded positively to the suggestion of

working closely with this local parent-run Association in the process of upgrading the CBR Project to include mentally slow children.

**Another good suggestion** was that the CBR collective, with its connections to the social services at different levels, could perhaps be instrumental in helping the local Association in Manzanillo become a province-wide and eventually national, government approved, Association of Families with Mentally Handicapped Children.

Participants recognized that in Cuba, as in the rest of the world, *change for greater inclusion and equal opportunities needs to be spearheaded from the ground up, through organized action by the less advantaged groups.*

## What happened to Cerebral Palsy?

Another disability that appeared to receive insufficient attention in the CBR program was Cerebral Palsy. In theory, children with CP are included in the broad category of Physical Disability. However, only a few Activistas said they were working with such children. When told there weren't many children with CP in Cuba, I found this hard to believe. Worldwide, the inci-

dence of cerebral palsy in countries both rich and poor is around 1 in every 300 live births. In countries with good maternal, pre-natal and peri-natal care, many cases of CP are prevented, and many brain-injured newborns are saved; so the incidence of CP remains about the same. Why should Cuba be different?

Nobody in Granma seemed to have statistics on CP. On my last day, a visiting health



This boy with spina bifida, a member of the Association of the Physically Disabled Persons, sings for the closing Evaluation Seminar of the CBR Project. He sings beautifully, and again impresses people with his strengths, not his weaknesses.

official from Havana told me that a recent survey reports an incidence of CP at 1.2 per thousand (about 1 in 800). I suspect this is too low. But even at 1.2 per 1000, the Activistas should have been attending many more children with CP. Part of the difficulty appears that on their medical reports at birth some of these children are diagnosed as simply "congénito" (congenital) or "retraso" (mental retardation), with no mention of CP.

On the average, half of all children born with CP are also mentally retarded. Since the CBR Project does not cover mental retardation, many of these children fall between the cracks.

Another problem is that the Activistas have been taught so little about CP that they don't recognize it when they see it. One Activista described a child whose body was "all twisted and stiff, with clenched fists." She was attending the child with the catch-all treatment plan for arthritis.

## Visit to a child with CP

After repeated requests I managed to see only one child with cerebral palsy. Ironically, this was an extremely disabled girl who lives in the municipal seat of Bartolomé Maso just 50 yards from the CBR headquarters. Urgent as her condition was, no one in the program was attending her! She is 15 years old but looks like she's 6. Just skin and bones.



This Activista in Monjara works with a partially deaf child and her mother. The child, who was at first very aggressive and badly behaved, has become very attached to the Activista, and her behavior has improved.

She is profoundly retarded, functionally blind, and epileptic. Her whole body is spastic and she has no body control whatsoever. Her greatest problem—which has become life threatening—is a C-shaped spinal curve, so extreme that her ribs on her right side press against her pelvis. The lung on that side is so compressed that she is in chronic respiratory distress. She has a lot of phlegm, which she has difficulty coughing up, and has difficult breathing.

The girl was not without medical care and other services. A family doctor visits the home regularly. A neurologist tried a spectrum of anticonvulsants to control the fits, and when none worked left the girl on a maintenance dose of Phenobarbital (counter-indicated in persons with respiratory compromise). A teacher trained in special education visits daily, though she does little more than provide moral support.

The girl was also been given a wheelchair. Unfortunately it was an adult chair, far too big for the small child. I suspect that her years in this chair is one of the causes of her life-endangering spinal curve.

One of the Activistas visiting the girl's home was asked to show me how she would respond to the needs of this child. (I felt sorry for both the Activista and the family, since the needs of this girl would have been a huge challenge even for a team of experts.) The Activista did her best with the limited training she'd received. First

she tried moving the child's arms. Finding them stiff, she began a series of rapid, water-pump-like exercises. That only made them more rigid.

This is where Mauricio and I, together with another very capable physiotherapist who was accompanying us, stepped in. It soon became an important learning session for everyone, including family members who contributed important ideas. Together we drew up a plan of action that included everything from teaching the mother about postural drainage (to drain the phlegm from the girl's lungs) to the design of a special seat to help her sit straighter, this to permit more space for the compressed lung.

I was delighted to see that Francisco—one of the disabled leaders who provides backup for the Activistas—had innovative ideas for designing the special seat. He offered to build it with the help of an elderly disabled carpenter who makes assistive equipment for the project we had visited earlier in the day. On discussing the needs of the little girl with CP in the "Evaluation Seminar" a few days later, Francisco demonstrated two cardboard models he had made of possible special seats for the child.

Everyone agreed that in addition to bringing mental retardation into the scope of their rehabilitation activities, they urgently needed more training, more instructional material, and more skilled backup to respond to the needs of children with cerebral palsy.



Billboards on Cuban highways don't promote Coca Cola or other corporate products. They promote the social ideals of the Revolution.

### Problem-solving with families—as equals

We also discussed the need for a more logical, analytical problem-solving approach to Activista training. We discussed the need for more interchange with the families—looking for solutions together, as equals—rather than simply giving people a routine series of *charlas*. This give-and-take, open-ended, egalitarian approach to problem solving is important not just for the Activistas and their instructors. In a society striving for inclusion and equality—as do both CBR and the Cuban Revolution—it is important for everyone.



This girl with cerebral palsy and profound mental retardation, although she received regular home visits from a family doctor, a social worker, and a special education teacher, had serious unmet needs.



In the sheltered workshop in Bartolomé Maso, deaf persons are recovering a traditional craft of making baskets and sombreros from thin flexible strips of wood they cut from a vine that grows in the Sierra Maestra. Cuba is increasingly focusing on reviving traditional arts, as well as indigenous medicinal plants.

We talked about the need for this approach to begin early, in the schools. If today's children are to become tomorrow's Activistas and "agents of change," schooling needs to become more participatory and discovery-based. Teachers need to learn how to draw ideas from their students rather than just push them in. Rather than just giving people routine instructions, everyone needs to learn to make their own observations and draw their own conclusions. Such is the education of "Activistas" in any truly revolutionary process. I believe that Ché and Martí would agree.



The US embargo against Cuba should be ended now.

In this context, we talked about the potential of the Child-to-Child approach in Cuban schools. Child-to-Child, in the empowering form developed in Mexico and other parts of Latin America, could serve a double purpose. It would be useful not just for "sensitizing" children about the needs and inclusion of disabled children, but also for facilitating a practical, open-ended, cooperative, discovery-based approach to problem solving. On these possibilities there was much thoughtful and productive debate.

**Need for more reference materials.** Finally, the Activistas felt that in addition to a longer period of both initial and follow-up training, with greater emphasis on logical problem-solving skills, to improve the quality of their work, what they most need is *more detailed and appropriate informational materials (mainly books)*.

The CBR team has worked hard to develop a wide range of instructional materials, guidelines, and handouts on the management of certain disabilities. Much of the information and illustrations have been taken from our books, *Disabled Village Children* and *Nothing About Us Without Us*. But too often the parts extracted are limited to specific exercises and activities, and little on evaluating needs and possibilities. Largely omitted has been the collective problem-solving

process, with disabled persons and families deciding what is likely to be most helpful, useless or harmful for a particular person and family in the local environment. As a result, Activistas tend to slip into a ritual of the same water-pump exercises for every person with a physical disability—as I witnessed on several home visits.

**Cuba's unique possibilities.** The above-mentioned shortcomings are seen in most CBR programs, not just in Cuba. Unique to the Cuban situation is that *the commitment to "inclusion and equal opportunity" is strongly shared, both by the CBR team and by the government at every level.* In this world, with its growing polarization between the haves and the have-nots, this is indeed a revolutionary commitment.



One form of "sensibilización" or disability awareness raising is through posters like these, held by CBR Activistas and program leaders at a meeting in Guisa, held at the primary school.

I agree with Handicap International's intention to continue supporting the CBR Pilot Project in Cuba for another 2 to 3 years, building on its strengths and working on resolving its shortcomings. Next year the Project intends to extend to another 2 municipalities. The plan afterward—when more wrinkles have been worked out—is to scale it up to the provincial and hopefully national levels.

In my view, the CBR program, together with the Cuban people and their government, can help this small island nation keep the Revolution moving forward on a path toward more caring and sustainable alternatives for this troubled world.

**Note:** A more extensive version of this report of Cuba is available on our web site: [www.healthwrights.org/articles/cubaCBRreport.pdf](http://www.healthwrights.org/articles/cubaCBRreport.pdf)

### HELP CUBA HELP ITS DISABLED PEOPLE HELP THEMSELVES

The field workers, or *Activistas*, volunteering in Cuba's Community Based Rehabilitation Program feel that with access to more detailed, appropriate information they could better help disabled children and adults meet their needs.

HealthWrights has made a commitment to try to supply copies of *Disabled Village Children* and *Nothing About Us Without Us* in Spanish to all of the 120 Activistas. They can't afford to buy them, as the basic wage in Cuba is \$5 a month. The books are produced and can be sent from Mexico. We need help to cover the costs. US \$12 will provide one Activista a book. \$48 will provide 4 books, or \$96 will provide 8 books.

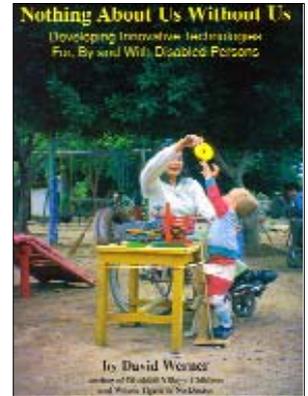
**Help us show the Cubans that not all North-Americans are blind to its achievements, or what it has to share with and teach the world.**



**Sharing of information, experience and hope** can be one of the most important roles that a community based program can play. Both HealthWrights and PROJIMO, through our books, newsletters, websites and interchanges with groups and programs in many countries, continue to “spread the word” about the health and disability initiatives with which we have been involved for many years.

**NEW! Books now online.** We are glad to announce that **all our health and disability handbooks are now available** online on [www.healthwrights.org](http://www.healthwrights.org) in both Spanish and English. These books can be freely downloaded and used anywhere on earth.

**NEW!** PROJIMO Rehabilitation Program in Coyotitan, Mexico has a **NEW WEB SITE:** [www.projimo.org.mx](http://www.projimo.org.mx) It still needs more work and volunteer help would be appreciated.



Also, the PROJIMO Community Based Rehabilitation team in Coyotitan, Mexico, has recently produced two “films” on their lives and work. The first of these is a video made with the help of the Rotary Club in Culiacan, Sinaloa. The second is a CD film made with the help of a North American volunteer, Peter Brauer. It is an educational, awareness raising CD created for and by spinal cord injured persons. To follow is a review of this remarkable production.

## **NEW! “Viviendo de Nuevo con Daño Medular”** —“Return to Life After Spinal Cord Injury”—

An educational CD “movie” on Coping with Spinal Cord Injury.  
Produced by the PROJIMO collective of disabled persons  
in Coyotitan, Mexico

Filmed and edited by Peter Brauer.

Currently available in Spanish, and with subtitles in English. 27 minutes.  
Price: \$US20.00 plus \$3.00 shipping. Profits go to PROJIMO.

This empowering educational production is remarkable in many ways:

*First*, it was **conceived and produced for and by spinal cord injured persons themselves**, as a visual form of peer counseling. Amateur filmmaker, Peter Brauer, spent 3 months working with the PROJIMO team, gradually improving the content, organization, and quality of the film as a collective learning experience for all. And because everyone volunteered their time and the filming was digital, the cost was remarkably low.

*Second*, it presents comprehensive, potentially **life-saving information** about spinal cord injury in a way that is **easily accessible** even for persons who cannot read or write. It draws on pragmatic advice from David Werner's handbooks, *Disabled Village Children* and *Nothing About Us Without Us*. Yet it combines this essential information with personal stories and experiences of spinal cord injured persons themselves (as well as children and adults with spina bifida).

*Third*, this 27-minute CD movie is **entertaining and up beat**. The paraplegic and quadriplegic protagonists show that **life with spinal cord injury can be as full of fun and adventures, intimacy and challenges to excel, as that of anyone else**. From the very start, their playfulness and antics take the weight off spinal cord injury, and replace it with hope, not for a cure, but for a happy and rewarding future.

The disabled educators who have created this CD—ranging in age from 10 to 40—skillfully show how to prevent and treat pressure sores and urinary infections, how to avoid and correct contractures, and how to make low cost protective cushions and assistive equipment. They demonstrate ways to cope with spasticity and even to use it constructively to perform certain tasks. But above all they show how spinal cord injured persons can relearn the skills of daily living, find ways to earn a living, and re-enter the life of the community as active participants and leaders.

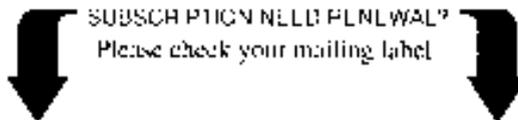
This astounding CD film will give a great boost to spinal cord injured persons and their families, to help them accept their disability and realize that they can still live rich and fulfilling lives.



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Please visit our World Wide Web site at:  
[www.healthwrights.org](http://www.healthwrights.org)  
 Also visit our new Politics of Health  
 Knowledge Network: [www.politicsofhealth.org](http://www.politicsofhealth.org)

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**Newsletter from the Sierra Madre #52**

**December 2004**

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**Please Note!**

If you prefer to receive future newsletters online, please e-mail us at: [newsletter@healthwrights.org](mailto:newsletter@healthwrights.org)



A blind musician who plays the guitar and sings beautifully, visited the CBR Center in Bartolomé Maso, and sang songs he had written about José Martí's vision of Cuba, and about the need to stop wars and conflicts between nations, so all of humanity can join together in world peace.

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*"It isn't the rebels that cause the troubles of the world, it's the troubles that cause the rebels"*

— Carl Oglesby  
*Students for a Democratic Society*