

# Newsletter from the Sierra Madre #25

## December 1991

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

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

**The Hesperian Foundation:** A small group committed to health rights and informed health care

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*In this newsletter we take a fresh, critical look at PROJIMO. Started as a program for disabled village children, it has gradually evolved, in response to a growing need, into a haven for physically and socially damaged young adults, many with spinal cord injuries resulting from the expanding subculture of alcohol, drugs, and violence. The PROJIMO team is trying to cope with the program's new role and to explore ways that PROJIMO can simultaneously serve vulnerable children and troubled young adults.*

*We also provide an update on the ongoing struggle for equality within PROJIMO itself, which in many ways parallels the struggle of the project's disabled members for equal treatment by society at large.*

## My Side of the Story

*by Juan Pérez*

*translated by Patrice Gormand*

*[Editor's note: Juan Pérez is a pseudonym for one of the sixteen spinal cord young adults who currently form an important part of the PROJIMO community.]*

I am going to tell you the story of my life. When I was five years old, my mother died. From then on, my father took charge of our family and life went on. But when I was ten, my father died. That's when I lost the rudder to my life. I suffered until I was thirteen years old. Then my life changed. I became friends with a man who offered to help me. He was the answer to my dreams because I was so tired of living in poverty, so tired of suffering. I thanked God for the opportunity to end my misery.

The first thing my friend did was to put me to the test. He gave me a 'package that weighed three and a half kilograms. He also gave me a .45 revolver. He warned me that in no case was I to lose the package; that my future depended on getting it to Mexicali. The package reached its destination, and when I returned, my friend was waiting for me. Not until then did I realize that the package I had delivered contained cocaine. "You've passed the test," my friend told me. "Do you want to keep working for me?" I told him I did, and he gave me some money. I felt I wouldn't have to suffer so much anymore.

My second job was to transport half a ton of marijuana to Nogales. This job changed my life completely, since the marijuana also made it to its destination. I was happy because life was smiling on me. I had everything I wanted.

I continued trafficking drugs for three years. Then one day my friend was killed by the federal police. I had learned enough about the business by then, so I decided to strike out on my own. My fortune began growing.

On a trip to Hermosillo, I met a young woman whom I liked a lot. I won her affections by showering her with expensive gifts. We went out for five months and then we got married. We were a very happy couple, but when our first child was born, we started having problems. I decided to get my wife a maid so that we could keep having fun. Soon after that my wife got pregnant again.

Two months later I was caught in Guadalajara with two kilos of cocaine on me. It was so hard for me to think that I might lose everything I had. I felt like the most miserable man in the world, fearing that I'd never see my wife and kids again. I was finally able to buy my way out of jail, but then I heard that my wife was cheating on me. I decided not to act without proof, but one day I found her

with her lover. I was all set to kill them. Only the thought of my children stopped me. What would become of them if they ended up as orphans, as I had? I left my wife and I allowed my children to go with her. I felt it was the best thing for them despite all the pain it caused me.

I decided to keep working. I lived surrounded by drugs and let them take over my life. I continued like this until I met my second wife. Now she was a real wife. We had a beautiful daughter together and I discovered a happiness I had never felt before. I retired from the business and became a rancher. And yet I felt I was doomed because I had so many enemies. I had no fear of dying; my only concern was for my daughter. I wanted to make sure that, if I were killed, she would still be taken care of and would never suffer.

When my daughter turned two years old, I decided to throw her a party, never imagining that it could be dangerous. I had her in my arms when a pickup arrived and several men started shooting at us. The first shots hit my wife and killed her instantly; then they hit me. With seven bullets inside me, I watched them kill my daughter. I pulled out my own gun and began shooting back. I managed to hit the pickups gas tank, making it explode. I had killed my wife's and daughter's assassins. Then everything went blank. *[Editor's note: One of the bullets passed through Juan's spine, paralyzing his lower body.]*

When I regained consciousness three days later, I couldn't remember what had happened. I thought my wife and daughter were there, but only my brothers' eyes gazed down at me. When I asked them where my family was, they began to cry. I told them not to worry about me, that I felt fine, even though I didn't - I just wanted to see my family. Finally, my oldest brother told me I must resign myself to the fact that my wife and daughter had died. I began to remember what had happened. I felt miserable. I cried. I felt guilty. Why did they have to die when they were not to blame for anything, while I, who was to blame, was still alive? I thought of killing myself, but realized that I wouldn't gain anything.

Instead, I told my brother that I wanted to get even with the man who had ordered me killed. My brother offered me his help, so I asked him to find a few men willing to do the job. He found four of them. They asked me how much I was willing to pay them. I felt such rage that I asked them to set the price. They did - at 30 million pesos. I agreed, with one condition: that I would be able to watch the man die. I wanted to see him suffer the same as I was suffering.

After two months, they found the coward and brought him to me. When I realized that he too had children, I ordered my men to bring me his wife and three kids. My anger was so great that I intended to kill them all. And yet, when they came before me, I realized I couldn't harm them. The man told me he had ordered me killed, not my family. I asked my men to take away the woman, who with tears in her eyes was telling me that she and her children were not guilty of anything and that I should forgive them. She said that her husband alone should pay for his crime. I finally told her to go away and take her children with her. She thanked me and left.

I told my men to kill my enemy bit by bit: to first pull out his nails, then cut off his hands and feet. The man pleaded and leaded for mercy, but. I enjoyed watching him suffer. As I took revenge on the man who had caused the death of my loved ones, I began to feel at peace.

After the man died, I felt there was no reason to go on living. I thought of killing myself, but I was never left alone. My brothers were always beside me, sharing in my suffering. I asked them to help me find a way to walk again. We went to many different places and saw many doctors. My fortune was almost gone when I finally realized it was all hopeless. All the doctors wanted was to make money. So I told my brothers we should just return home. I spent months alone just lying around at home, thinking about the past. One day, however, my brothers brought me news about a program for disabled persons called PROJIMO, in Ajoya They offered to take me there, and having nothing more to lose, I agreed to spend some time there.

As the days and months went by, I felt myself making progress. Now I am happy because I don't have problems. I've retired from the business and spend my time volunteering at PROJIMO. I feel happy because, even though I'm paraplegic, I can live in peace. *[Editor's note: "Juan" became one of the leaders of the volunteer group.]*

I would like for people to think about my experiences. The type of life I was leading is dangerous; often innocent people pay for one's mistakes. It's as if one killed them oneself. It's a terrible experience to go through such a painful period, but some of these things are just destined to happen. I hope that you understand and never do what I did. It's nice to have money, but the kind of money I had is a man's ruin. People lose their lives for it, they are jailed for it, they lose their loved ones for it. . . This is the end of the life story of a man who still regrets his bad fortune.

## Where Have All the Children Gone? Project PROJIMO's Coming of Age

The Program of Rehabilitation Organized by Disabled Youth of Western Mexico - better known as PROJIMO - is now ten years old. Members of the PROJIMO team, most of whom are disabled themselves, are now engaging in a process of participatory assessment. They are asking such questions as: *What has been the program's overall impact? In what ways have we succeeded or failed? Where do we go from here? What have we learned that may be helpful to other self-run groups of marginalized people struggling for equality and self-determination?* What follows is a preview of some of their key findings.

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### ***Project PROJIMO today is no longer a center primarily for children.***

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PROJIMO was started in 1981 as a rural 'community-based rehabilitation' (CBR) program run by disabled villagers to serve disabled children and their families. In this form, the program has served as an inspiration and model for concerned groups of disabled persons, parents, and health workers in many parts of the world. PROJIMO has helped stimulate the launching of at least eight programs in different parts of Mexico, as well as many in other developing countries, that have to varying extents adopted the PROJIMO grassroots self-help approach. The manual *Disabled Village Children*, which largely grew out of the PROJIMO experience, is now being used worldwide. Translated into thirteen languages, it has been described by UNICEF as a landmark book that has "probably influenced more people working on projects for children with disabilities than any previous work."

So the impact of PROJIMO has been substantial and positive in several important ways.

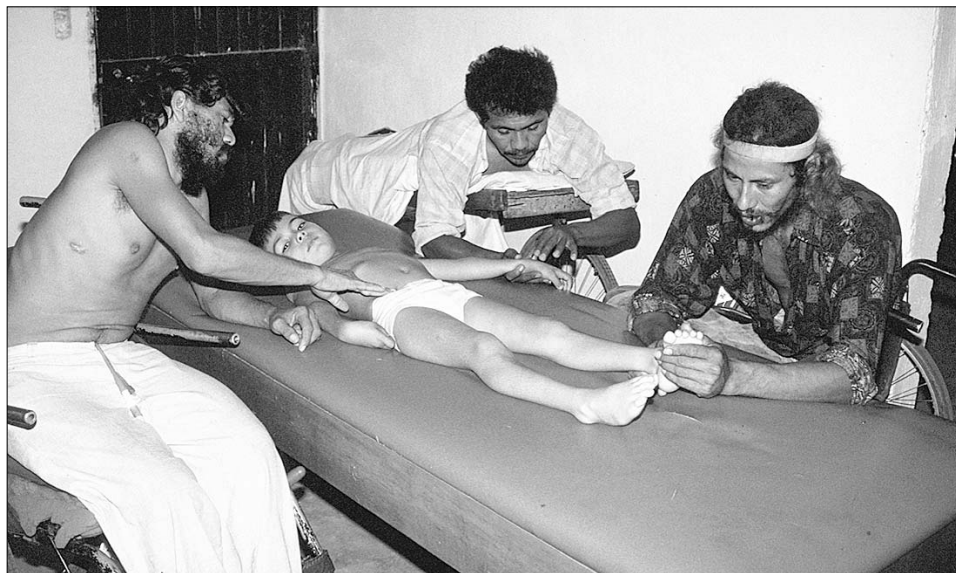
But has the project failed in other ways? And has it been true to its goals?

The answers to these questions depend on how we choose to look at things. Paradoxically, sometimes it seems that the strengths of the program have grown out of its weaknesses.

One thing is certain. For better or for worse (or both), over the last few years PROJIMO has changed. These days the first big question visitors usually ask is, "Where have all the children gone?"

Sadly (at least for some of us), today Project PROJIMO is no longer a center primarily for children. In fact, 'El Proyecto' has acquired such a fearsome reputation that many parents—while they still bring their children during the daytime for consultations, brace-fitting, and custom-made wheelchairs—would not dream of letting their child stay (as parents used to) for long-term rehabilitation and skills training. If we evaluate PROJIMO strictly as a program to serve children - its original mission we must conclude that during the past three or four years it has increasingly failed.

If, however, we assess the program in terms of its ability to evolve and address changing human needs as they arise—and to take on even greater challenges—then perhaps PROJIMO can be judged less harshly. The transformation of PROJIMO from a peaceful program for disabled children into a rough-and-tumble center for physically and socially disabled young adults has taken place in a gradual and completely unplanned manner in response to a growing, desperate, and otherwise unmet need. It happened like this.



Three spinal-cord injured young men massage Angel, a six-year-old boy with muscular dystrophy.

## Responding to the needs of children with spinal cord injury

In the first years of PROJIMO most children brought to the center had disabilities caused by polio or cerebral palsy. Other disabilities ranged from birth defects, club feet, muscular dystrophy, and juvenile arthritis to sensory deficiencies, developmental delay, and epilepsy. With the occasional help of visiting 'rehab experts', but mostly through learning by doing, the team of disabled villagers gradually acquired the necessary skills to help these children and their families meet a wide variety of needs.

**Julio** It was not until 1983 that the first youth with spinal cord injury entered the program. Fifteen year-old Julio had been shot in the neck two months earlier by his younger sister when they were playing with their stepfather's pistol. He was left paralyzed from the neck down. When he arrived at PROJIMO, Julio was little more than skin and bones, severely anemic, and very depressed. He had a deep, necrotic pressure sore on his buttocks which had destroyed the base of his spine. He had a fever from the infection.



Because Julio was the person with the least power physically at PROJIMO, he was given a job that gave him more power socially: recording the hours worked and wages earned by each worker. Here he writes with a plastic pen holder strapped to his hand.

The team of disabled villagers was hesitant to accept Julio. They felt ill-prepared to meet his needs. Clearly, the boy needed hospitalization and expert nursing care. But to their dismay they learned that Julio's sores and infections had developed in a hospital. The doctors had sent him home in his present state, presumably to die.

Julio's home situation, likewise, was far from ideal. While his mother did what she could for her paralyzed son, his stepfather resented the attention she gave to the boy, whom he said would be better off dead. Especially when drunk, the man made life unbearable for both mother and son.

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*In most Third World countries, people with spinal cord injuries usually die within one or two years after becoming paralyzed.*

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On arrival at PROJIMO, Julio begged his mother to let him stay. The team's heart went out to the boy. Wisely or unwisely, they voted to accept him into their group.

Working with Julio was not easy. The team had to learn about treatment and prevention of pressure sores, use of catheters, bowel programs (regular use of a finger to stimulate defecation), and dysreflexia (crises of high blood pressure). And because Julio's body does not sweat below the level of his injury (the neck), the team had to guard against his temperature rising dangerously high. Sometimes, when the electricity fumed during a heat wave, they had to take turns wetting down his body and fanning him around the clock. Once he nearly bled to death after the team tried to remove the rotten flesh from deep inside his pressure sore.

All in all, through their work with Julio, the PROJIMO team learned many new skills for managing spinal cord injury. These ranged from medical and nursing care to training for wheelchair use, transfers, exercise activities, and measures for self-care and independent living. Usually Julio was fun to work with because he responded so eagerly and so well. But sometimes he still got depressed.

Recognizing that physical rehabilitation was just the start of helping to meet his needs, the team encouraged Julio to assume responsibility at the center in various ways. Using a simple device that allowed him to hold a pencil, Julio worked for a while keeping track of the hours worked by team members records that determined their pay. (Thus the person with the least control over his body was given greater control in the program. This helped to even things out in terms of people's relative power.). Later Julio spent several years working as shopkeeper of the government-subsidized collage store (CONASUPO).

Today Julio remains active in the program. He periodically travels alone on the bus to visit relatives. Deciding that it is time to become self-reliant, he recently applied to the Hesperian Foundation's revolving loan plan (for which we are seeking donations - see below) to set up a small billiard hall in his grandparents' village.

Julio's arrival at PROJIMO was soon followed by an influx of other spinal cord injured children and young adults. Among the first to come were Vania and Jérica.

Vania was first brought to PROJIMO at the age of eight by her ailing great aunt. She had been shot through the spine when she was one year old, as a result of a drunken brawl in the house

next door. Shortly after her injury her father abandoned the family; later her mother committed suicide.

At PROJIMO Vania blossomed. Within a few months she had metamorphosed from a scrawny, louse-ridden, forlorn little girl into a lovely, self-confident child. She quickly learned to provide nursing care and perform the bowel program for a younger spinal cord injured child named *Jésica* (See *Newsletter #17: "Lupe, the Wildcat."*)

*Jésica* became paraplegic from an injection in her backside that became infected, received when she was three days old. When she arrived at PROJIMO, she was unable to walk. The village team corrected the clubbing of her feet using a series of plaster casts. In a few months *Jésica* began to walk with plastic leg braces and a wooden walker - all made at PROJIMO. Soon she was walking to school.

### **Paraplegic young women become program leaders**

Two spinal cord injured young women who came to PROJIMO in its early years were Mari and Conchita. Both have become strong leaders in the program.

*Mari* became paralyzed in her lower body as a result of a car accident on her honeymoon, after which her husband abandoned her. Refusing to accept her disability or even to sit in a wheelchair, she attempted suicide twice before coming to PROJIMO. But in PROJIMO, by helping others in need, she quickly recovered her will to live. Mari has become a gifted clinical evaluator of the needs of children with a wide range of disabilities. And she is a superb peer counselor. Speaking to newly arrived

spinal cord injured persons on the basis of her own experience, she helps them to accept their disabilities and get on with their lives. Mari is now married to one of the other disabled PROJIMO workers and has a little girl named Lluvia. (Mari's story is recounted in *Newsletter #16.*)



Mari and Lluvia

*Conchita*, who injured her spinal cord in a fall, has become one of the most responsible members of the PROJIMO staff. She does the book-keeping, coordinates learning activities (work and play) for the younger and more severely disabled members of the PROJIMO family, is involved in the ongoing program evaluation,



Conchita and Miguel with their two children

and is now learning to make artificial limbs. She is married to an able-bodied village youth, manages their small mud-brick home, and has two lovely children. (Conchita tells her story in *Newsletter #22.*)

### **The rising tide of young adults with spinal cord injuries**

PROJIMO's achievement in helping to meet the complex needs of persons with spinal cord injury is unusual for the Third World - and is explained largely by , the fact that, in this self-run program of disabled people, spinal cord injured persons take the lead in learning from and helping one another.

In most Third World countries, people with spinal cord injury (SCI) usually die within one or two years after becoming paralyzed, often from either severe pressure sores or urinary tract infections.

In Mexico the situation is now somewhat better than in many poor countries. Emergency surgery after spinal injury tends to be fairly good (although the costs often devastate families economically). However, nursing care and rehabilitation in most hospitals still leave much to be desired. Patients often develop pressure sores and urinary tract infections while still in the hospital, and are sent home with little or no instruction on how to prevent or manage these life-threatening problems.

Back at home, persons who are quadriplegic (paralyzed from the neck down), and in many cases even those who are paraplegic (paralyzed below some point in the back but retaining full use of arms and hands), tend to remain totally dependent on their families.

Becoming increasingly wasted, contracted, and depressed, they gradually die from boredom and infection. Comprehensive rehabilitation services, although improving, remain few and far between, and tend to be authoritarian, ritualistic, and demeaning. Too often these programs fail to deal with the needs of the whole person.

Not surprisingly, therefore, the 'good news' about PROJIMO's care for people with spinal cord injuries rapidly spread far and wide. Increasing numbers of 'paras' and 'quads' began to show up from every corner of the country: to date PROJIMO has served over 200 spinal cord injured persons. After rehabilitation, many choose to stay longer and help others. An increasing number of the leaders, workers, and skilled crafts persons of PROJIMO are persons with spinal cord injuries.

### **Impact of the growing 'culture of violence'**

The growing number of spinal cord injured participants, however, has led to unforeseen changes in the nature and focus of PROJIMO. First, it has meant that the program now serves many more young adults. Second, many are spinal cord injured from bullet wounds. Most are young men (along with a few young women) whose injuries have resulted from involvement with alcohol and use and/or trafficking of drugs. They mostly come from the underworld of the cities, from the rapidly growing, 'culture of violence', or (as they call it) la vida mala. When they show up at PROJIMO, many bring with them their habits, their anger, their violence - and frequently their alcohol and drugs.

Understandably, parents are often afraid to leave their disabled children in such a setting. So, as the number of difficult young adults in the program has increased, the number of children has dwindled.

What should the team do? Throw the offenders out? Close the doors to potential troublemakers? These are not humane options. Those who are both physically disabled and alcohol- or drug-dependent are in a sense in the most desperate need of all. Many have no home to go back to, and can only return to the streets and bars that place even the able-bodied at high risk. Besides, some of the roughest and most dissipated of these young men also have very positive, even gentle sides, and great potential. At their best, many are hard working, and show sincere appreciation for the assistance and respect they get at PROJIMO - which for most may be their last chance.

One of the secrets of PROJIMO's success - and perhaps also its 'tragic flaw' - is that it tends to err on the side of lenience and flexibility, rather than law and order. It almost always goes people a second chance, and then a third. It tries to focus on people's strengths, not their weaknesses.

The team realizes that the culprits are also victims. Even some of the persons with the most violent criminal backgrounds turn out to be very human individuals trapped by circumstances. At their worst, they seem heartless. Yet they may be surprisingly loving and tender with the loneliest or neediest disabled child.



Martín Pérez gives a young friend a bath

**Juan**—whose autobiographical sketch begins this newsletter—is an example. He has killed, tortured, and trafficked drugs. But as he tells his life story, it is hard to be judgmental, at least as we normally view things. When he was a hungry, orphaned child, the good guys were the bad guys and the bad guys good. The government, the police, the upstanding citizens all let him starve in the streets. The man who finally rescued him, who gave him food, clothing, and shelter, was a drug trafficker. By reliably delivering cocaine, the boy proved his honesty. And later, by not killing the wife and children of the man he tortured to death, he showed compassion.

This is the same Juan who, while at PROJIMO, terrorized an elderly diabetic schoolteacher during a drunken binge. And it is the same Juan who, just a few days later, became enthusiastically involved in giving special therapy to a six-year-old boy with muscular dystrophy. Juan's gentle touch and genuine concern had a marvelous effect on the child. When the boy first arrived, he had been fearful, whiny, and completely dependent on his mother, crying when anyone else came near him. Just a few days later, he was self-assured around other people, and quite enjoyed his therapeutic exercises, which Juan imaginatively turned into games.

The root problem lies, not in these 'deplorable' young people, but in the society that deplores them. It lies in the mushrooming city slums, mounting homelessness and unemployment, and the widening gap between rich and poor. It lies in the systematic undermining of agrarian reform measures, which forces more and more poor farming families off the land into the 'septic fringe' of the cities. It lies in the international forces that impose devastating 'structural adjustment' and 'free trade' policies on debt ridden poor countries. It lies in the corrupt authorities and profit-hungry entrepreneurs, from the level of a small Mexican village to that of a giant multinational corporation, who promote alcohol consumption for personal gain. It lies in the phoniness and brutality of the so-called 'War on Drugs', which scapegoats the little guys who deal drugs to survive, while turning a blind eye to the kingpins and to official complicity (which extends to top levels in Mexico City and Washington). It lies, ultimately in the poverty and racism which, through our callous indifference, we allow to persist in many areas of the US, spawning the despair that largely fuels the demand for drugs which producers and traffickers in Mexico and elsewhere in Latin America respond to. In short, the growing problem of alcoholism, drug use, and violence can be traced to the undemocratic nature of our so-called democratic society.

### **Grassroots democracy at PROJIMO**

Both PROJIMO's remarkable successes and its managerial failures can be largely traced to its commitment (at least in principle) to equal rights and equal representation. Part of the difficulty in trying to resolve major problems is that the motley collective tries so hard to be democratic, to reach decisions through a group process in which everyone supposedly has equal say.

As disabled persons, many of the team have come from a disadvantaged position in their homes and communities. Often they describe their participation in PROJIMO as

"liberation from a prison." still licking their wounds, they have an almost militant passion for equality. They demand to be masters of their own destiny, not only as a group, but also individually. They want no bosses, no directors, no supervisors, no board of directors, nobody lording it over them or telling them what to do. So fierce is this feeling of political independence that all attempts to effectively manage or organize the program have been repeatedly thwarted.

With a touch of pride, the team speaks of PROJIMO not as an organization, but as a 'disorganization'. From time to time they have made various attempts at electing 'coordinators', often on a rotating basis. But the group invariably gives the coordinators such a hard time that soon they throw up their hands in despair. So most decisions - from large to trivial - are still made in meetings of the whole group in which everyone has an equal say - or at least the right to an equal say.

In reality, of course, the group has its self-appointed leaders, its unofficial pecking order, its manipulators of group opinion and decision making. Leadership tends to be all the more susceptible to abuse because it is unofficial, and therefore unaccountable. In PROJIMO, as in the world at large, democracy - like the pot of gold at the end of the rainbow - is much pursued but never quite realized.

Nevertheless, the relentless struggle of 'those on the bottom' for equal rights is perhaps humanity's only hope for a decent world. The PROJIMO collective's basic commitment to equality among all its participants, while at times leading to chaos and disorganization, still allows some remarkably positive things to happen.

### **Grassroots revolution within the disabled community**

PROJIMO draws no clear line between care providers and recipients. Nearly all PROJIMO workers first came to the project to receive rehabilitation. From the time they arrive, everyone - including children and their parents - is asked to help out in any way they can. What and how much they do depends on their abilities and level of interest. After their initial needs are met, participants who choose to stay and learn more skills often gradually make the transition from clients to staff. At first, their work is volunteer; they receive only room and board. When their work improves, the group may vote to give them a token salary - and eventually, perhaps, a full salary (which is just a little above Mexico's minimum wage).



Quique teaches Spanish to a North American physical therapist.



Raymundo, a brace maker and wheelchair builder at PROJIMO, has found an effortless way to relieve the pressure on his backside and prevent pressure sores while relaxing.



The PROJIMO community - mostly disabled young adults - tend to fall into two groups: those who work for pay and those who do not. For the most part, those who are paid have greater physical abilities (although many are in wheelchairs) than those who are unpaid (some of whom are quadriplegic or have other disabilities limiting use of their hands). Although in theory all participants, paid and unpaid, have the same rights and voice, in practice - until recently - the paid workers clearly often have had the upper hand. In spite of all the theorizing about equality, there remained vestiges of a two-tier system.

In February of this year, differences between the paid and unpaid groups came to a head. Due partly to careless overspending of project funds, at the end of the month there was no money to pay wages. The Hesperian Foundation, which provides an 'auxiliary fund' to cover the difference between the value of services/equipment provided and what families are able to pay, refused to come to the rescue.

Suddenly caught without wages, some of the paid workers came together to seek solutions. One of them later explained: "We were so threatened by not being able to cover expenses that we decided to form a group of eight people who have been at the project longest and who have shown more responsibility and care for its goals. The decision was difficult, but we knew we couldn't bring about the necessary changes in the larger group setting. We needed a small group to begin looking for ways to improve our financial situation." He readily admitted that "The group of eight coordinators came about without the entire consensus of the large group," but explained this by saying that "Motivation in the community had degenerated to the point that nobody seemed to be interested in the selection."

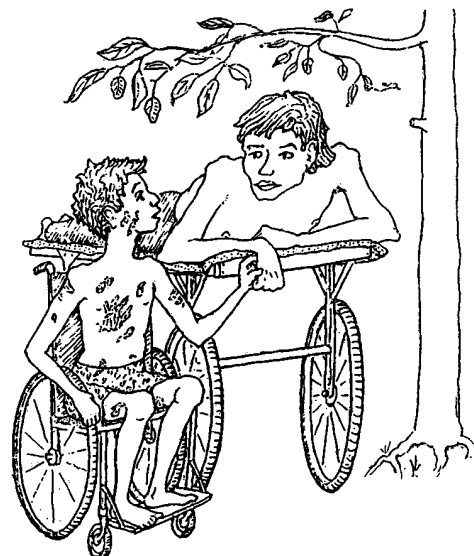
This self-pointed 'coordinating group', soon dubbed the 'Group of Eight', came up with a plan which they presented to the larger group. According to their analysis, PROJIMO's economic crisis came from having too many non-contributing members. They pointed to the growing number of long-term residents who had gone as far as they were able or willing to in their rehabilitation, did little or no work, yet continued staying at PROJIMO because they liked it and it was free. They noted that many of these non-contributors were the same persons who constantly broke the rules about drinking and drug use on the grounds, thereby giving PROJIMO a bad name. The Group of Eight suggested that the freeloaders either convince their families to pay the cost of their food and care, or else go home.

The fuse was lit. Over the next few days, a groundswell of protest brewed among the unpaid participants. "What right has the Group of Eight to impose their mandates on the larger group? "It sounds fine to say 'pay up or go home' - but what about those of us who have no money and no family?" "All they want is to protect their own salaries!"

The unpaid group began to organize in self-defense. At the next all-group meeting they confronted the self-appointed Coordinating Group with their own self-appointed 'Volunteer Group'. Their main spokesperson was Enrique (Quique) who is quadriplegic and depends almost completely on attendant care.

Quique is one of the 'old guard' at PROJIMO. He has spent most of the last six years there, having arrived a few months after he fell backwards off the top step of a baseball bleacher when drunk and broke his neck. When he first arrived he was so covered with pressure sores that it was impossible to put him in any position without his lying on several sores. So the team made a special bed for him out of adjustable, padded slats. He needed almost constant turning and care, which he submitted to with anger and curses. He drove even his most committed attendants, including Mari, to tears and despair. During a crisis of infections he suffered several cardiac arrests.

But little by little Quique has come around. Although his mood shifts with the political winds of PROJIMO, he is usually cheerful and outgoing. Indeed, he has become an



effective peer counselor and Spanish teacher. Many of the spinal cord injured youths who have passed through PROJIMO, on looking back, warmly recall that it was Quique's friendly companionship and wry humor that helped nudge them from self-pity to renewed hope.

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Quique is also good with unattractive children whom others tend to avoid. There was a mentally delayed ten-year-old boy named Jose, who could barely walk or speak, but who creatively and repeatedly smeared himself with his own shit. When the rest of the PROJIMO team were too busy to have anything to do with him, the boy would spend hours sitting in the mango grove beside Quique's wheeled stretcher talking with him.

The confrontation between the two groups was spirited. From their 'bottom-up' perspective, 'Quique's Group' (as the Volunteer Group became known) presented a very different analysis of PROJIMO's crisis and a radically different plan for economic recovery. Their argument went something like this:

*The Group of Eight claims that we, the unpaid members of PROJIMO, are the cause of the economic crisis. They say we consume resources and contribute nothing. So they want to evict us.*

*However, there are other causes of the shortage of money - causes that the Group of Eight seems to forget, although they have been repeatedly discussed, though never solved.*

*We contend that the paid workers - not us - are to blame for the money shortage. We, the Volunteer Group, are determined to correct this situation and thereby save enough money to meet costs without evicting anyone.*

*First, we all know - and it has often been discussed - that many of the paid workers report more hours than they actually work. We volunteers will keep track of and record the hours they really work. This should save us a third of the money now spent on wages.*

*Second, a lot of program money ends up in private hands. Often money paid by villagers or welding and repair jobs is pocketed, while PROJIMO pays for wages and materials. Also, goods produced for program self-sufficiency - such as the plastic woven chairs - are sometimes sold after hours, and the money pocketed. Even tools and medicines have been secretly sold.*

*By keeping careful watch, the Volunteer Group hopes to put a halt to all these losses. We want the paid workers to give us their keys to the shops and the consultation room. We will make sure that all money charged for program work or supplies goes into the common fund.*

*Third, we will voluntarily do some of the work now being done by paid workers. Some of us have strong hands. We*

*can help each other with exercises, bathing, and even treating pressure sores. In addition, we can sweep and clean up the grounds, a job people are now paid for, but rarely do. With our help fewer paid workers will be needed. This will save still more money.*

*Fourth, we will double check the bookkeeping and monthly financial reports.*

*In short, we want to provide the kind of management that PROJIMO sorely needs. This will be our contribution. We are confident that we can save the program more money than would be saved by throwing us out.*

*All in favor say "Sí."*

And the majority voted "¡Sí!"

To the credit of the Group of Eight, although some clearly felt threatened by the proposal of 'Quique's Vigilantes', they accepted the volunteers' plan with good grace. They knew that each of Quique's points had a basis in fact, and that never before had anyone come up with such concrete ways to deal with the problems in question.

At the next large group meeting, the paid workers in charge of the shops and consultation room, all members of the Group of Eight, ceremoniously put their keys in a metal box on Quique's wheeled stretcher. Quique grinned with enormous satisfaction.

### **Keeping the new leadership in line**

In terms of the process of democratization, this grassroots revolution within PROJIMO has been one of the most empowering events to date. It was exciting to see the same battle for equality that PROJIMO has waged with the 'outside world' repeated within its own ranks of disabled persons. After all, fairer distribution of power is what the struggle for health is all about.

For a while, the uprising in PROJIMO really seemed to make things better. The Volunteer Group kept tab on the paid workers, who suddenly got a lot more work accomplished. And the volunteers did a lot of work themselves. Every morning they raked and swept the entire grounds, which now looked cleaner than they had for years. Quique began to earn income for the program by selling soft drinks from an ice chest next to his stretcher. All in all, the checks and balances of the Volunteer Group to curtail 'capital flight' worked so well that in the following months not only did the budget balance, but the back

wages for February were paid. It was a fresh start for PROJIMO.

But revolutions seldom fully live up to their ideals, especially once they are won. As long as the Volunteer Group was seeking equalization of power and authority, the situation improved. But soon its members' expanded power began to go to their heads. They began to give some of the paid workers, especially the women, such a hard time that some of them threatened to quit. Then Quique quarreled with Martin P., the head of the wheelchair shop, and tried to use his newfound influence to throw Martin out of the program. Martin, who is known for his creativity and violent temper, left the program in protest, saying he would not return until Quique gave him back his key. A meeting was held, and this time the group voted that all the keys be returned to the heads of the shops.

Quique saw this reversal of the team's previous decision as a coup. Infuriated, the Volunteer Group went on strike, refusing to work or cooperate in any way. Within days, the rounds were once again dirty. And to top it off, Quique's group conducted a 'drink-in'. They spent all the program's profits from soft drinks on liquor, and boozed it up under the mangos.

The drunken festivities went on for days. Not until the group threatened to throw Quique out of the program did things more or less return to normal.

After swinging back and forth for several months, the pendulum of power in PROJIMO is at last steadying. The two groups are trying to work together. The Coordinating Group invites members of the Volunteer Group (Quique and Julio) to join their meetings. The volunteers are again fulfilling some of the responsibilities they had assumed. Overall, the balance of power is perhaps a little closer to midline than it was before the February Revolution.

### **Bloodshed and reconciliation**

On September 1 an act of drunken violence forced the team toward radical corrective steps. Sadly, the victim of the violence was one of the most gentle and vulnerable members of the group, a retired schoolteacher named Hector who had arrived only three weeks before.

Ironically, earlier that day Hector had told visitors how deeply he appreciated all that PROJIMO had done for

him. Hector is diabetic. He had come to PROJIMO to have a prosthetic limb made for his amputated leg. But his biggest worry was that he had lost his voice over a year ago, and the doctors had told him he had cancer of the throat. Utterly disheartened, Hector had all but resigned himself to dying. In PROJIMO, finding himself surrounded by so many severely disabled persons who refused to give up, he got his second wind. Almost miraculously, his voice returned. Or, more precisely, he learned to whisper loudly enough to make himself understood.

"I can't tell you how thankful I am to PROJIMO," he told everyone who would listen. "It's a marvelous program and an inspiring group of people. They have given me new life!"

That night at 2:00 A.M., two of the spinal cord injured young men, Juan and Manuel (a pseudonym), wheeled into Hector's room stone drunk and switched on the lights.

"What can I do for you?" asked Hector, rolling over in bed.

"We're bloodthirsty men," said Manuel, "and we're going to be leaving PROJIMO tomorrow. We want to leave with blood on our hands. So we're going to kill you."

"But I hardly know you!" gasped Hector in his hoarse whisper. "Why me?"

"Why not?" replied Manuel. He rolled up to Hector's cot and pulled a large kitchen knife from the side of his wheelchair.

Shouting for help with the loudest whisper he could muster, Hector did his best to ward off the knife blade with an electric fan. He suffered a slash across the side of his nose, and several small cuts on his arm.

The next day, a marathon six-hour meeting was held under the giant fig tree to discuss what had happened and what action to take. Hector was still in a daze. Instead of expressing anger at his attackers, he seemed bewildered. He kept repeating the question, "Why me?", as if he had done something wrong, or had himself somehow brought disgrace to the program. Generously, he agreed not to go to the police with his grievance, but to let the group figure out what to do.

The start of the meeting was delayed because Manuel and Juan - who had been sober when the group assembled - temporarily disappeared. (It is a PROJIMO policy not to publicly discuss or criticize people without their being present.) Twenty minutes later the two young men rolled in, their cocky self-confidence rekindled.

"Too bad," someone said, "that you lack the balls to meet with us sober."

"You lie!" barked Manuel. "I haven't been drinking!" He glared defiantly at the group, his wild, shoulder-length hair framing his heavy, intelligent face. Then he added, almost inaudibly, "Just a couple of beers to get rid of the hangover."

In addition to everyone from PROJIMO, the meeting was attended by Roberto and Flor (Florentino), both organizers for farmworkers' rights, and Miguel, a village doctor. All three have had close links to PROJIMO in the past, and often act as informal advisors. Roberto and Flor have waged personal battles to overcome alcoholism, and have helped others do so, both in the village and in the program.

Flor and Roberto set a rational, humane tone to the meeting. They stressed that while last night's violence had to be dealt with, it was only a symptom of a much larger problem, both within and outside PROJIMO. It was this bigger problem which the program urgently needed to deal with. Throwing last night's attackers out of the program would do little to resolve the underlying problem, they suggested, and in some ways might add to it. Something must be done to get at the root of the problem. A supportive network and environment were needed which would allow persons like Manuel and Juan a better chance to free themselves from their harmful habits and offer them more attractive alternatives.

Nearly everyone agreed, and suggestions were made. However, much of the discussion focused on whether Manuel should be kicked out of the program or not, and, if so, temporarily or forever. In the end, it was Manuel himself who burned his bridges. Primed by alcohol, he was surly and aggressive. (By contrast, Juan remained silently in the background and was soon forgotten.)

Instead of apologizing for what he had done (as he had done just before the meeting), Manuel accused the group of making him a scapegoat. He made a big issue of an occasion when some of the paid workers held a beer party

in the wheelchair shop in violation of PROJIMO rules without any group action being taken. "The Group of Eight is just looking for an excuse to throw us volunteers out of the project," he complained, fanning the flames of the old dispute. "They're always after the underdog!"

When someone mentioned that there was a big difference between having a few beers and terrorizing a defenseless old man, Manuel snapped that the real difference between the two incidents was that between favoritism and persecution.

The meeting dragged on and on. A few people did most of the talking. And no conclusions were reached. After five hours a secret ballot was taken, with four alternatives. The majority voted that Manuel should leave the program for three months, and only come back when he was committed to do his best to avoid drinking, drugs, and violence.

When the final tally was announced, everyone seemed a little shocked. For all its squabbling, power struggles, and infighting, PROJIMO is still in many ways like a big family. For many, PROJIMO is home, or the closest thing they have had to home in many years. And, as the poet Robert Frost put it, "home is the place that when you've got to go there, they've got to take you in."

One advantage of the meeting being so long was that Manuel eventually sobered up: By the time the vote was taken, he was less defensive and even a bit remorseful. He accepted the group's decision that he leave for three months and thanked them for agreeing to let him come back to try again. Since his accident, he said, PROJIMO had been the first place where he had felt life was worth living. He wanted to come back and learn skills to help other people. But for the time being, where, he asked, could he go? He had no money, no friends he could stay with. His only relatives were on the far side of the country, in Campeche. And he had overstayed his welcome with them, too. The youth center in Campeche had also expelled him.

With the group's permission, Manuel stayed another two days at PROJIMO, until a ride could be arranged to Culiacán (the state capital), where Más Válidos, a community-based rehabilitation program started by two PROJIMO 'graduates', is located. Unfortunately, Más Válidos has experienced problems not unlike those in PROJIMO, and has discontinued its 'live-in' facilities. They let Manuel stay only three days. With no place to go, he very quietly returned to PROJIMO. Completely sober and on

his best behavior, he stayed out of everyone's way, slept on the floor in a corner of a porch, and silently worked from dawn to dark in the garden and cleaning up the grounds. He appeared to be doing penance.

For their part, those at PROJIMO - uncomfortable with either asking him to leave or letting him stay - pretended not to see him.

Meanwhile, there was a lot of discussion about the larger problem: the growing number of young people disabled through substance abuse and violence; the inability of PROJIMO to cope with the large numbers of these young adults coming to it for rehabilitation; the impact that the drinking, drug use, and violence are having on the integrity of the program and its ability to serve the needs of children.

Everyone was asking the big questions:

- Is there some way that PROJIMO can again become a safe and peaceful place for disabled children?
- Can we find a better way of helping disabled young adults who have become caught up in alcohol and drugs to shake their habits and assume a constructive role in society?
- Is it possible to work simultaneously with children and troubled young adults?

Many people thought the best solution would be to split the program in two. A separate house at the far end of the village could be rented to serve as a center for the young people with alcohol and drug habits. In this way PROJIMO could once again become a program primarily geared to children. Perhaps those young adults who gained enough control over their habits could come to the main PROJIMO facility during the daytime for skills training and to work.

Good idea, as far as it goes. But who would provide guidance for the young adults in their separate location? If their drinking, drugs, and outbursts of violence already make them unmanageable at PROJIMO, what would they be like on their own? Without a skilled counselor - preferably a peer who had personally experienced addiction to alcohol or drugs - would they not be a dangerous liability to themselves and the entire village?

But how could such a skilled peer counselor be found?

It was Julio - who himself has been intermittently caught up in alcohol and drugs, and last year was almost kicked out of the program - who helped lead the group toward a promising and humane solution.

"Are we throwing Manuel out just to punish him?," he asked. "Or to help him? If throwing him out of PROJIMO does him more harm than good, what does anybody gain? On the streets, is he likely to give up drink and drugs? Or become less angry and violent?"

"Surely," Julio continued, "if we kick Manuel out for three months, we should find a place that will help him control his drinking and learn something useful. That way, we will all benefit when he comes back to PROJIMO."

Everyone thought this was a great idea. But where to send him? Someone suggested a program in Culiacán called Ten Thousand Friends which helps wayward youth addicted to alcohol and drugs. But arrangements had already been made for a boy from the villa to go there to try to break his alcohol habit. The place is run by a group of very proper psychologists and social workers, and the boy soon felt so alienated and bored that he left. Somehow it didn't sound like the right place for Manuel.

Then someone remembered having read about a program in Guadalajara called *Centro Anti- Albergue de los Reyes* (Hostel of the Kings Anti-Alcoholism Center).

The *Albergue de los Reyes*, a sort of live-in Alcoholics Anonymous program, was started and is run by recovering alcoholics who help one another quit drinking and get a new start on life. The key to each person's success lies in helping others who are worse off. Equally important is the support and encouragement that participants receive from each other. Just a few weeks after entering the program participants are helping to nurse, feed, and clean up after the newest arrivals. At any one time, more than 100 alcoholics stay in the center, helping one another kick the habit. Although there is a constant turnover, a few of the most experienced and skilled peer counselors keep the whole process on track.

### **Possibility of an albergue in Ajoya**

Suddenly several people had the same bright idea -one that might help solve several problems at once. Might Manuel be interested in spending his three months away from PROJIMO at the Albergue de los Reyes? He could

go with a double purpose: 1) to try to end his dependency on alcohol and drugs, and 2) to learn peer counseling techniques that would enable him to help others kick the habit. If all worked out well, Manuel just might be the person to help start a similar albergue in Ajoya for disabled persons hooked on alcohol and drugs.

Manuel was excited about the idea. So the next step was to get in touch with the leaders of the Albergue de los Reyes. Contact was finally made by telephone. As anticipated, the staff of the Albergue were enthusiastic about the plan, and especially about training Manuel to play a lead role in setting up a similar program in Ajoya. They said that for years they had been looking for the opportunity to help start a similar program, and this was their first chance. The leaders from Guadalajara have even offered to make trips to Ajoya (about 500 miles away) to help get the new center started.

### **An anti-alcohol center for the whole village**

The tentative plan is to set up a hostel in the village of Ajoya, separate from the main part of PROJIMO, for disabled young adults hooked on alcohol and drugs. But before launching such a plan, it is essential to discuss it with the village as a whole. Villagers are already upset about the incidents of alcohol- and drug-related violence at PROJIMO. The idea of setting up a whole new center for such people may not be well received.

However, the village may welcome an AA-type hostel if it provides assistance, not only to disabled persons, but also to able-bodied young people in the village who are trying to get off alcohol and drugs.

The fact of the matter is that Ajoya desperately needs such a program. For years' the village has been a 'hot spot' of alcohol trade and drug trafficking. 'hot spot' a crossroads between the mountains and the coastal plain, the village serves as a trading post and gathering place, and has always had something of a rough-and-tumble "Dodge City" flavor. But now it has become a meeting point where drug dealers from the coastal cities and growers of poppy and marijuana from the mountains come together to do business. Until recently there was very little drug use by local people. But now that Mexico has become a major avenue for trafficking South American cocaine into the United States, big-time dealers have begun to bring cocaine into the village. They offer cocaine to young people to get them hooked, and then swap cocaine for opium gum and pot.

Roberto and Flor estimate that between 40% and 70% of the young men in Ajoya regularly use or have at least tried cocaine. The number of youths who are alcoholic or binge drinkers is also high. Violence is commonplace. This summer in Ajoya a 16-year-old boy was shot to death.

Many teenage boys begin to drink or do drugs with their buddies because it is the macho thing to do. By the time they reach their early twenties, if not before, they become hooked. As they mature, many desperately want to kick the habit, but given the circumstances find it almost impossible.

A hostel somewhat similar to the one in Guadalajara could be a lifesaver for village youths who are emotionally and socially disabled by alcohol and drugs. If the spinal cord injured young men running the hostel manage to control their own addiction and then help some of the village youths to do likewise, they would be making a major contribution to the community.

Time and again, disabled workers in PROJIMO have demonstrated that out of their weaknesses grow their strengths. This happens through a process of helping and learning from each other. PROJIMO's new goal is to use the same approach to help those with addiction to alcohol or drugs.

### **Conclusion**

At present, the plan for an Alcoholics Anonymous type hostel in Ajoya still exists only on paper. But the first steps have been taken. Manuel has traveled to Guadalajara by bus, where he has been welcomed with open arms by his peers at the Albergue de los Reyes.

If the idea becomes a reality, the PROJIMO team may have stumbled upon an innovative way to simultaneously serve disabled children and socially traumatized adults. What at first glance appears a sad step backwards may prove an exciting advance.

Note: As this newsletter goes to press, PROJIMO is launching an exciting new initiative: an intensive Spanish program for disabled travelers, health workers, activists, and others from the US and elsewhere. If this program is successful, the project will have taken a major stride toward financial self-sufficiency thanks in large part to the efforts of the PROJIMO members who have in the past been labeled 'non-contributors': the more extensively disabled individuals who will be doing much of the teaching.

## PROJIMO's Offspring

The number of disabled children at PROJIMO has dropped in part because the number of difficult young adults has grown. But there are two other reasons for the lower number of children at PROJIMO, both of which are largely a result of PROJIMO's long-term success.

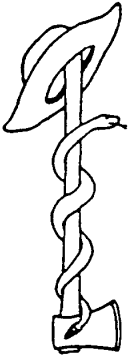
First, when PROJIMO began, there were no other rehabilitation facilities in the region offering the same full range of services at low or no cost. As a result, there were hundreds of seriously disabled children who had never received adequate attention. For example, scores of children of all ages, paralyzed since infancy by polio, were unable to walk because they had never been fitted with braces and crutches and their legs had become contracted. Now most of these children have had such needs met. To date, PROJIMO has served over 2,000 disabled children, in effect extending its coverage to a wide surrounding area. *Thus the declining number of children seeking attention at PROJIMO is partly a reflection of how many children have now been effectively reached.*

Second, many of the children who used to come from a great distance - especially from the coastal cities - today go to similar rehabilitation programs nearer their homes. Some of these community programs have been started by or had important input from persons who had previously anticipated in or trained at PROJIMO, or who have otherwise been influenced by the PROJIMO approach to community-based rehabilitation. Here are some examples:

- In Culiacán two disabled young men, Jesús and Juan, started the Más Válidos program after coming to PROJIMO for their own rehabilitation. They spent more than a year at PROJIMO mastering the necessary skills. In PROJIMO's early years, it treated hundreds of children from Culiacán (a distance of about 150 miles). Now Más Válidos meets most of these children's needs.
- In Mexico City, Dolores, a rehabilitation specialist who took part in a PROJIMO training course and has remained in close touch ever since, helped start a community-run rehabilitation program called SERESAT. The organization now has branches in three of the city's poorest communities. Dolores V. is also helping to start another branch of SERESAT in Michoacán.
- In Puerto Vallarta, two former members of PROJIMO who have a little girl with cerebral palsy have started a program called Proyecto Pitillal, which is run for and by disabled people and their families. Several young disabled persons from this program have received training in brace making, wheelchair making, and other skills at PROJIMO.
- Also in Mexico City, Eduardo, a doctor affected by polio, has been working on starting a PROJIMO-like O-like program as part of Campamentos Unidos, a community architecture program that helps earthquake victims build their own houses.
- In Mazatlán, Dolores, a wheelchair-riding participant in PROJIMO, has long been active in Los Pargos, an organization of families of disabled children. Periodically this program brings a busload of children to PROJIMO. Recently Dolores also helped to found an independent living organization in Mazatlán of which she is vice president.
- In Hermosillo, Sonora, Polo, a young man disabled by polio who in his teens spent three years at PROJIMO and became a master wheelchair builder, has helped set up a wheelchair repair shop as part of a program for disabled persons.
- In Tijuana, Baja California, Gabriel, a paraplegic young man who went to PROJIMO for rehabilitation, is a leader in a new program of disabled persons and is setting up a wheelchair shop.
- In at least twelve municipalities of the state of Sinaloa, the director of CREE (Center for Rehabilitation and Special Education, a government program) has set up rehabilitation outposts attempting to follow the PROJIMO model.
- In Campeche, Alberto (a pseudonym), a refugee from Guatemala who spent two years in PROJIMO, has begun a wheelchair-building program in the refugee camp where he live previously.

Most of these programs - and several others that are getting started in different parts of México maintain close ties with PROJIMO, send disabled participants to PROJIMO for skills training, and take part in training programs and workshops. A loose network has formed linking these and other community based rehabilitation programs in Mexico.

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**Newsletter from the Sierra Madre #25**

**December 1991**

**In this issue:**

An update on recent developments  
at Project PROJIMO, featuring:

- its evolution from a program for disabled children into one for spinal cord injured young adults, many of whom come from Mexico's growing subculture of drugs, alcohol, and violence.
- its continuing internal quest for equal rights and democracy.