



# Newsletter from the Sierra Madre #64

May, 2009



**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)

*In February 2009, David Werner facilitated two workshops on innovative technology for and with disabled children and their families—and with mediators from Stichting Liliane Fonds (SLF), a charitable organization in Holland that helps disabled children in difficult circumstances. David was accompanied by his long-time friend Allison Akana, who filmed the workshop in Lima.*

## Hands-on Workshops with Disabled Children in Peru by David Werner

The workshops were held in Lima and Chimbote, two cities on the western seaboard of Peru. The lifelines to these oasis-like towns in the vast coastal desert are sinuous rivers fed by the rapidly shrinking glaciers of the Andes.

**Lima**, with its swelling population of over 12 million, is now home to nearly half of the country's 28 million inhabitants. My first impression of Lima was how much its bustling commercial zones resemble those in the USA. From my hotel window overlooking a noisy thoroughfare I viewed the towering billboards of Burger King, KFC, and Pizza Hut.

Yet the prosperous midtown of Lima is surrounded by a metastasizing "septic fringe" of abject poverty. The rapid periurban growth has been due to a mass exodus from the countryside, where decades of violence between revolutionary movements, abusive government troops, paramilitaries, and drug cartels have forced millions of poor families to flee their ancestral lands. Vast numbers of these internal refugees have squatted in makeshift *invasiones* (shanty towns) on the slopes surrounding Lima.

**Chimbote** is a sprawling fishing town of around 300,000. In times past, Chimbote was a relatively prosperous community, due to the abundance of tuna and other large fish in the coastal waters. Until recently Peru supplied up to 10% of the catch for the international fish market. But as a result of over-fishing,



Some of the workshop participants stand with David Werner next to a placard announcing the pre-workshop seminar in Chimbote, which was held in the auditorium of the Municipal Hospital.

human contamination of sea water, and global warming, in recent years there has been a precipitous decline in the fish population in Peruvian waters. This ecological demise has caused escalating unemployment and poverty, especially in large fishing towns like Chimbote. The coastal deserts offer few other options for employment. Impoverished settlements have sprung up on the barren sand dunes surrounding Chimbote, as is the case with other smaller cities on the northern coast.

**Peru is a land of stark contrasts**, geographically, culturally and economically. As in so many countries of Latin America and the world over, the widening gap between rich and poor has led to growing social and ecological instability, which is reflected in smoldering unrest, crime and violence. Revolutionary movements such as the Sendero Luminoso (Shining Path) and

the Tupac Amaru (MRTA) started off with high egalitarian ideals. But as these insurgent groups got caught up in drug trafficking, extortion, and kidnapping to finance their "revolution from below," they gradually lost their popular support.

Under the crushing inequality of the current social order, it's no surprise that many young people turn to drugs and petty crime—as result of which the well-to-do incarcerate themselves in gated communities with razor-wire fences and armed guards.

The assistive technology workshops in Peru, like those I've facilitated in other countries (see Newsletters #53/54, 55, and 62 on [www.healthwrights.org/newsletters.htm](http://www.healthwrights.org/newsletters.htm)), had **3 inter-linking objectives, which increasingly are becoming fundamental to the concept of Community Based Rehabilitation (CBR):**



Wheelchair access remains a big problem in Peru, even in public buildings. This guest speaker in Chimbote confronted these stairs at the hospital auditorium where our disability seminar was held. Participants helped carry her up.

1. To demystify and de-professionalize (i.e. popularize) the process of rehabilitation—including the making of low-cost assistive devices, adapted to each child's possibilities, wishes, and needs.
2. To encourage professionals and service providers (including Liliane Fonds mediators) to work with the disabled children and their families as partners in the problem solving process.
3. To seek the full inclusion of disabled persons in society through a holistic approach that brings together the social and technical aspects of habilitation.

On the first day of the workshop the participants (25 in Lima, 27 in Chimbote) divided into small groups of 3 to 4 persons, to visit the homes of pre-selected disabled children. After befriending the children and their families, and observing their needs and environment, the children, family members and participants explored possibilities together and decided on one or more assistive devices that might help the child do something better, or to make life happier. That afternoon,

## Lima Workshop

In the Lima workshop 24 participants, in 8 small groups, worked in partnership with 8 disabled children and their families to create more than 25 assistive devices.



**Jorge.** When workshop participants visited a 10-year-old boy named Jorge, who has congenital muscular atrophy, they found him sitting in an unusual wheeled seat made by his uncle, who turned out to be an “ergonomics engineer.”

The visitors invited Jorge's uncle to the workshop—where he was a great help with technical aspects of several assistive devices.



Although Jorge's uncle had designed and built a special therapeutic seat for Jorge, he



Like most cities around the world, Lima has not escaped the American junk food industry.

on returning to workshop venue, each small group made posters summarizing their child's situation, needs, and wishes, and drew sketches of the assistive devices they planned to make the next day.

On the second (last) day the workshop we began with a brief plenary session where each group—together with the child and relatives they'd visited the day before—presented their ideas and designs for possible



At the opening plenary Jorge's uncle explains the therapeutic features of the unique seat he had built for his nephew.

preferred to sit in the wheelchair he'd been given. With great effort he could move it a little bit by himself. Doing so was even harder because the backrest had been fitted with a thick cushion sculptured to accommodate his spinal deformity.



While this thick backrest did nothing to correct the deformity, it positioned the boy so far forward that he had to reach far back to reach the wheels. This made it almost impossible for him to propel the wheelchair with his very weak arms.

assistive devices. Then each group—the course participants, the child and family members all working in partnership—spent the day creating, testing, and adapting their respective assistive devices. Finally, in the last hour of the workshop, everyone gathered in a closing plenary where the children demonstrated how well their new assistive devices worked. All had a chance to make helpful suggestions, applauded the successes, and drew final conclusions from the process.

Both the Stichting Liliane Fonds (SLF) workers, and the occupational therapists and other professionals brought a wealth of good ideas to the workshops, but most had little practical experience using hand tools or in designing or making assistive devices. Fortunately, a number of fathers and other male relatives took part in the workshops. Many of these men had the carpentry and technical skills that a lot of the mediators and other participants lacked.

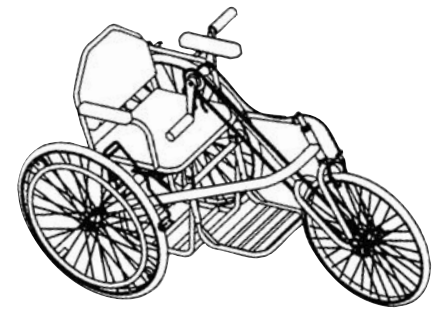


What Jorge's family said they most wanted was some kind of corset or support mechanism that would help him sit with his back straighter. What Jorge said he most wanted was to be able to propel his wheelchair more easily, without having to reach so far back. The visiting group made drawings showing these concerns—which they presented the next day at the opening plenary of the workshop.



To help the boy sit in a straighter position, Jorge's group, with the help of his mother and uncle, fitted his wheelchair with a set of carefully placed padded supports. These they made out of pieces of cardboard glued together which they covered with foam. He now sat much straighter in his wheelchair.

Improving Jorge's wheelchair mobility was more than the group felt they could do in the workshop. But in response to his wish, a plan was made for Jorge's uncle (the ergonomics engineer) to work with John Oliveras, a local physiotherapist who builds custom-made wheelchairs, to make a hand-powered tricycle. The tricycle will be geared so low that Jorge can move it—slowly but surely—with his very weak arms.



**Weight-watching!** An added benefit to be gained with such a tricycle is that the exercise he gets by riding it around could help him lose weight. (A low calorie diet was also recommended.) *Indeed, for children like Jorge, avoiding of obesity may be one of the most important factors in their rehabilitation.*

### Carlos and his father



One of the fathers most eager to take part in the workshop in Lima was that of Carlos, a 15-year-old with severe cerebral palsy and developmental delay. Carlos' mother died when he was a baby. He lives alone with his father in a tiny room on the third floor of a run-down tenement in an impoverished neighborhood.



Victor Hugo Merino Conde, the coordinator of SLF in Peru, greets Carlos on our pre-workshop home visit.

His father, who is very poor, has a lot of dignity and a kind heart.

At the opening plenary Carlos' group and his father present the plans for his son. They hope to make him a simple, collapsible sitting frame so his dad can more easily sit him up on the bed to feed him. They also showed designs for adapting the wheelchair to better meet the boy's needs.



Carlos and his group at the closing plenary.

At the closing session, Carlos' group presents how they modified his wheelchair so he can sit up straighter. They added an adjustable overhead bar to hang toys from, in the hopes this will stimulate him to lift his head and begin to use his hands.

Clearly, Carlos' biggest needs could not be resolved in the workshop. But now a dialog has begun between his father, the local mediator, and the SLF coordinator, to look for better solutions. One idea is to have John Oliveras, who cooperates with SLF, design a wheelchair with an attached cart, so that Carlos' father can take his son with him when he sells food on the streets. A friendly neighbor who lives on ground level has offered to take care of the wheelchair when not in use, so that Carlos' father doesn't have to haul it up and down the hazardous stairs.

One important aspect of the workshops, together with the home visits, is to get a feel for the child and family's overall situation, and to open the way for a continuity of opportunities and assistance so that the child's basic needs can be met and quality of life can improve.

The room has no electricity, no running water, and no windows. There isn't enough space to unfold the big wheelchair the boy was given. And the steep narrow stairs to get to the room are precarious.

To subsist from day to day, Carlos' father is a street vendor. He cooks potatoes and eggs on a tiny portable camp stove, and sells them at small repair shops. Away most of the day, he locks his helpless son in the room all day, lying on their single bed.

While this may sound like neglect, the neglect is not that of the father, but of a society that doesn't adequately reach out to those in need. The father is devoted to his son and given the circumstances does the best he can for him. We found the boy clean and well nourished.



At the opening plenary Carlos' group and his father present the plans for his son.

## Chimbote Workshop

In the Chimbote workshop 27 participants, together with 6 disabled children and their families, made more than 20 assistive devices. Also they adapted an assortment of poorly fitted wheelchairs, leg braces, and other equipment that the children had been using (or, more often, not using—because they were uncomfortable or didn't work).



### Estrella.

Estrella is a 6-year-old girl in Chimbote with spastic cerebral palsy. When workshop participants visited her home, they found the child strapped into a fancy oversized donated wheelchair. The adjustable chair

was tilted so far back that it triggered the girl's spasticity, arching her body backward out of control.



Estrella's spastic pattern is triggered by the reclined position of her wheelchair.

In the workshop the next day, Estrella's group tried to adjust her wheelchair to a more upright position. But it was corroded in place and wouldn't budge. (Nobody had ever shown the family how to adjust it.)

The solidarity of disabled people and their families helping one another is fundamental to the empowering potential of CBR. With this in mind, the local SLF mediator in Chimbote, Margarita, invited a disabled mechanic to assist in the workshop.

Estrella's group made several useful modifications to her wheelchair. They raised the footrests to reach her feet. They made a thick cardboard back cushion to help her sit in a



Estrella's group attempts to adjust her wheelchair.

less slumped position, thereby reducing her extension spasms. And they made a headrest with wide wings, to help keep her head from twisting so far to one side when she went into spastic extension.



Estrella's group asked this hemiplegic mechanic for help. In a short time he succeeded in putting the chair into a more upright position. Everyone was impressed—by his ability, not his disability.

With her **modified wheelchair**, Estrella was able to sit more upright, with her hips at a right angle to her back. This way she could sit more relaxed, with less spasticity—which let her do more things for herself.



BEFORE



AFTER



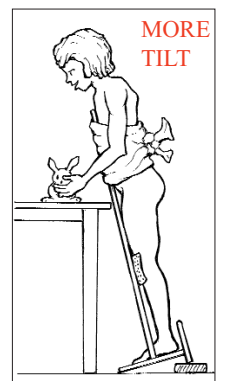
Estrella's group also decided to make a **standing board** to help her gain more body and head control.

At first Estrella's head tended to thrust backwards. They found that by increasing the forward tilt of the standing board, she could hold her head better, with less spasticity.

### Adjusting the tilt of the stand for better head control:



When the board was inclined only slightly, her head tended to flop backwards in spastic extension.



But by tilting the board forward more, she had less spasticity and better control. This allowed her to look down in front of her, and she began to play with things with her hands.



**Max**, from Lima, is a clever 12-year-old with athetosis (constant uncontrolled movements of his body). Although he can't speak, with gestures and sounds he manages to communicate quite well.

Max had been prescribed plastic leg braces (AFOs) to prevent foot deformities. But he hated them! — and with good reason. They pressed painfully on the bony prominences on his feet causing sores and calluses.



One thing Max indicated he wanted was an adjustable tray on his wheelchair, to help him learn to draw and write. Here, during the home visit, he demonstrates his potential.



Max's older brother was a big help at the workshop. Here he extends the armrests of Max's wheelchair, to support a tray.



Now Max's braces no longer hurt him. He was thrilled!

**“A key feature of these workshops was the active participation of a wide range of brothers, sisters, and other young family members. This was in keeping with the philosophy of Child-to-Child—emphasized in the seminars—where school-aged kids learn to include and assist children with special needs.”**



At the workshop the therapists (OTs and PTs) were reticent to try to modify the braces so as to take the pressure off the bony spots. So together we taught Max's grandmother and older brother how to heat the plastic to soften it, and then bend it to create small protective indentations over the bony spots. (We used a heat gun, but in the home a candle or kitchen stove will do.)



Max himself also did his best to help. Here he holds the cloth that will be used to cover his tray.



Max's grandmother and older brother learn how to adjust the braces by heating and bending them.



At the final plenary Max and his group present their handiwork—including the wheelchair tray, a cardboard backrest cushion, a head stabilizer, and his modified (now pain-free) leg braces.



## Daniel

One of the children for whom the greatest number of assistive devices were made, allowing him to do more things he wanted to do more easily, is a bright 10-year-old boy in Lima, named Daniel. Daniel was born with arthrogryposis—or joint deformities which give him very limited movement of both his upper and lower extremities—which means there are a lot of things he couldn't do for himself. He was unable to use his hands to feed himself or push his wheelchair.



Daniel moves his chair by rocking it.

However the boy is very innovative. He'd learned to move about independently in a small chair without wheels by rocking it from side to side by movements of his body.

He had also learned to write and paint with his mouth—and was doing fairly well in school.

When the group visiting Daniel's home asked him what he most wanted to be able to do better, he said he wanted to write and draw more easily, and be able to eat with a spoon. To do these things, he thought an adjustable stand fixed to a table on his wheelchair might be helpful. The group asked him to draw a picture to show what he wanted.



The next day at the workshop, Daniel's group—together with him, his mother, aunt and his eager 8-year-old brother, Angel—presented their observations and designs in the opening plenary.

Posted on the wall with their other designs was Daniel's mouth drawing. It showed himself in his wheelchair. On a tray was mounted a slanting stand, on which he drew with a pen attached to a head-



Daniel and his group also experimented with a wrist band holding a spoon, and an arm support for leverage, until he was able to lift the spoon to his mouth. Here he shows how he can now eat by himself with a spoon.



During the workshop Daniel's brother Angel—and Daniel himself, as best he could—helped sand the pieces of plywood to make his adjustable drawing stand."



Daniel and his brother, Angel, present Daniel's mouth painting of himself showing his idea for a headband pen-holder and a desktop easel.

With the help of his mother, aunt, and his brother, Daniel's group made a wide variety of additional assistive devices, including extensions to the brake handles



At the closing plenary Daniel proudly shows how he can take colored marking pens from a simple foam-plastic rack with his mouth, and draw using his new wheelchair tray and adjustable stand.

on his wheelchair, and puzzle-like games to help improve the very limited use of his hands. All in all, the group made a dozen different assistive devices for the boy. Daniel and his family were delighted.

At the start of the workshop Daniel had seemed very shy and reluctant to speak out. But by its end the boy had a lot more self-confidence. And his whole family had more hope for his future.



Daniel shows how he can play computer games with a head band and pointer made by his group. He learned to use it very quickly.

## Paper-Based Technology

In the workshop I encouraged the participants, in creating their assistive equipment, to experiment with “Paper Based”—or better said—



### Leysi

The most outstanding cardboard seat was made for a little girl named Leysi. Her group was excited to try out the new (to them) paper-based technology.



One of the mediators made a small cardboard model of the seat they planned to make.

“Cardboard Based Technology” as it is described in my book *Nothing About Us Without Us*. It largely consists of building special seating and other aids out of sheets of cardboard from old cardboard boxes, glued together

er in layers to form lightweight plywood-like boards. These homemade cardboard panels, are low-cost, easy to work with, and very adaptable. To my delight, several groups decided to experiment with cardboard technology.



Several family members helped out. Leysi’s 11-year-old brother, when he wasn’t taking care of his little sister, eagerly assisted with the construction of the seat. And Leysi’s mother and sister helped with the upholstery.



Here the group tests Leysi’s new cardboard seat for fit. It is vital to make sure that the seat fits properly before adding upholstery.



In the final plenary, Leysi’s mother proudly shows how her child sits in her elegant new seat.



### Alejandro

Alejandro is a vivacious little boy with dystonic cerebral palsy who at nearly 2 years old still cannot walk without assistance. His family, which is very poor, lives in a

Twice a week Alejandro’s mother takes him, at considerable sacrifice, to a community rehab center where he practices walking with an adult-size walker that is far too big for him.



woven reed (estera) hut in a new squatter settlement on the desert sands outside Chimbote. No water. No electricity. No vehicular access. We hiked across the dunes to get there.

Alejandro’s mother thought her son would learn to walk more quickly if he had a simple walker to use at home. So the group decided to make a small wooden walker, based on designs in *Disabled Village Children*.



Alejandro and his mother stand in the doorway of his hut.



Here, in the workshop, Alejandro helps to make his own walker.



Alejandro tries his new walker. Both he and his mother were delighted!

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This issue of **Newsletter from the Sierra Madre** was created by:

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*The greatest terror a child can have is that he is not loved, and rejection is the hell he fears. I think everyone in the world to a large or small extent has felt rejection. And with rejection comes anger, and with anger some kind of crime in revenge for the rejection, and with the crime guilt — and there is the story of mankind.*

— John Steinbeck—*East of Eden*, 1952

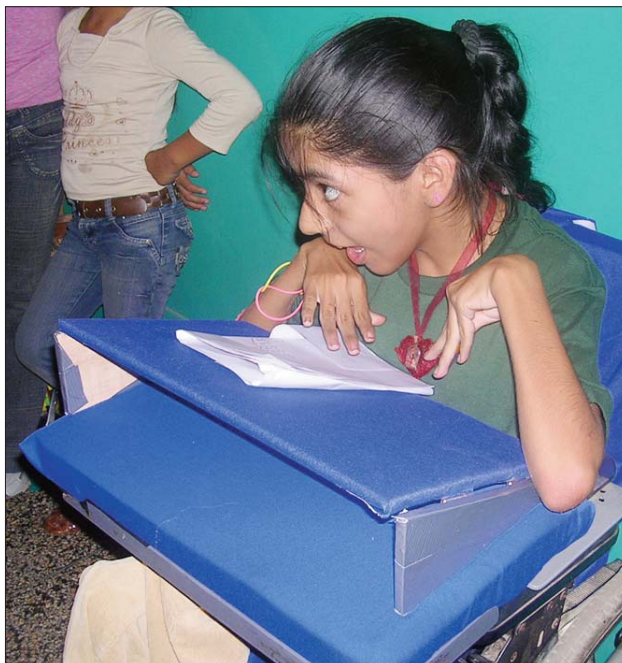
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Workshop participants in Peru adapted Ada's wheelchair to better meet her needs, adding a special backrest, cushion, and a table with an adjustable stand for better hand control.

