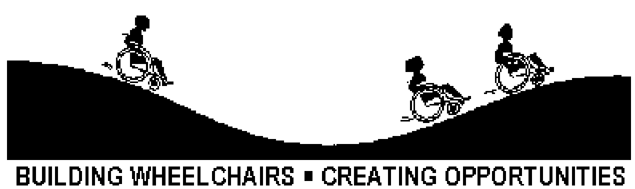
Part Four

WHEELS TO FREEDOM

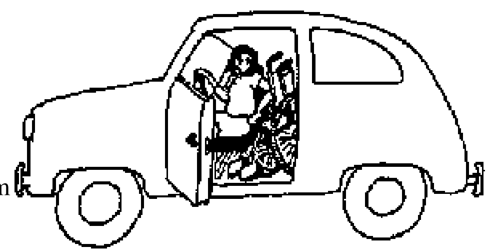


INTRODUCTION TO PART FOUR

Designing Mobility Aids to Meet Individual Needs

Wheelchair riders understandably get upset when people say they are "wheelchair confined." Nobody, they say, calls a bike rider "bicycle confined." For someone who cannot walk, a good wheelchair can be a doorway to freedom. It is liberating, not confining.

But if assistive devices - including wheelchairs - are to help disabled persons reach their potential, they must be carefully selected, designed, and adapted to meet each individual's unique combination of needs. In this book's Introduction we saw how standard wheelchairs from the North, donated to 4 women in different countries and circumstances, proved unsatisfactory. This was because the providers did not take into account the particular *needs and wishes of each individual*. Nor did they consider *cultural factors, living conditions, local terrain, available transport, or questions of accessibility*. By contrast, we saw much better results when such factors were taken into account, and when needs and possibilities were discussed with the disabled person and family as part of a creative, problem-solving approach.



Even when persons with the same disability live in the same town, their needs for equipment may vary, depending on their lifestyle, options for schooling or work, and other factors. Cost and convenience must also be considered.

For example, before the wheelchair builders at PROJIMO make a chair for a person, they ask if the chair will need to be transported in a motor vehicle, and if so, what kind. To fit into a passenger car, it helps if the chair can be folded.

But, if the chair will be carried in the back of a truck, folding may be less important. For many families, keeping the price down may seem more essential. A non-folding chair can be made at lower cost, is lighter weight, and is often more trouble free.

In this part of the book we look at the needs of different persons, not only for **wheelchairs**, but also for other equipment in the realm of "wheeled mobility." This includes**wheeled cots, (gurneys, trollies)** and **hand-powered tricycles**. Our emphasis is on development of a particular mobility aid to meet the specific needs, circumstances, and possibilities of an individual user. For this reason we often describe the situation in story form, and may sometimes include the development of other innovations for the same person.

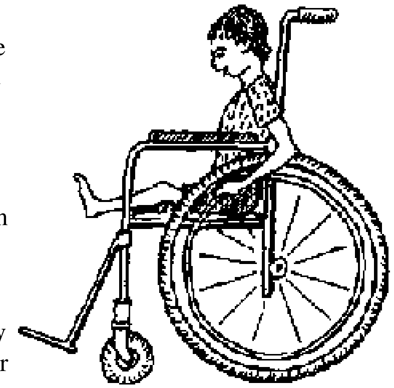
Wheels work for getting around only when there is access to where you want to go. This means everything from sufficiently smooth, firm **walkways** and **roads**, to **ramps** and in some cases **lifts** or **elevators**. In Chapter 35 we describe a low cost elevator with gravity lift.

In this book we do not include detailed instructions on design and production of standard wheelchairs. Four very different wheelchair designs are in the book, *Disabled Village Children*. Details for building the excellent, low-cost **Whirlwind Wheelchair** are found in *Independence Through Mobility*, by Ralf Hotchkiss (see p.343). Here we do, however, include some of the most recent breakthroughs in the Whirlwind design (in Chapter 30).

OOPS! THINK AGAIN!
- The Importance of Deciding With, and Not For, the User

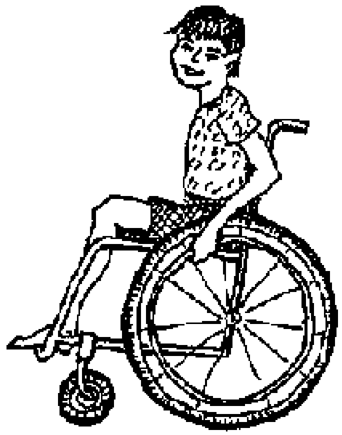
One day, two persons from PROJIMO visited the home of a disabled child in the city of Mazatlán. The child's mother told them about a neighboring family with two children who could not walk. "They're smart little kids," she said, "but their bodies are too weak to walk."

Together, the mother and the PROJIMO workers went to visit these neighbors. They found the two children alone in the house with a baby sitter. The sitter was friendly and invited the visitors to examine the children, who were playing on the floor. It appeared that the children had an inherited muscle weakness, perhaps some form of muscular dystrophy.



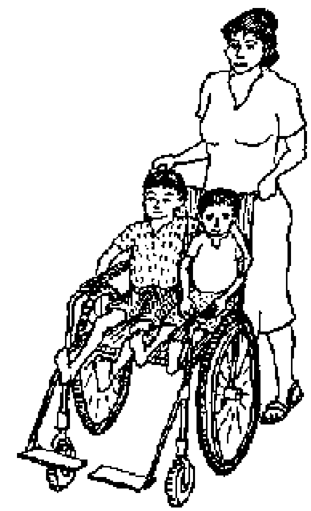
MARCOS, the older child, was six years old. He pointed proudly to a big wheelchair in the corner. "Put me in my car!" he insisted. The wheelchair, donated by a government family aid program, was adult size. The small boy sat in it with his feet sticking out over the front edge of the seat. He tried to move the chair by pushing on the wheel rims, but had to stretch his arms far apart to reach them. The chair was so heavy, he could barely move it.

"We have a small, light wheelchair in Ajoya that should fit him much better," said one PROJIMO worker. "We will bring it on our next trip."



And so they did. The chair fit Marcos well. Although his arms were quite weak, he could move it about slowly in places where the ground was level and fairly smooth.

On this visit the children's mother was home. The PROJIMO workers suggested that she trade the big chair for the small one. But she insisted on keeping the big one. **The PROJIMO workers explained all the reasons why the small chair was more appropriate:** "Marcos sits in a better position. He can move it by himself. It is lighter and takes up less space. And, because the seat is lower, with practice he may learn to climb into and out of it by himself."



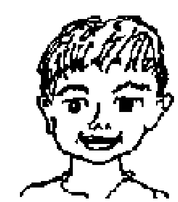
The children's mother listened politely, then said, **"But you don't understand! For us, the big chair is best.** You see, I don't have a husband. I sell tacos in the street market. Often I don't have any money to pay a baby sitter. So I have to take both children with me to the market. **In the big chair I can seat both of them together!"**

That was something the PROJIMO workers had not thought of. Given the circumstances, the big chair meets the family's needs better than the small chair.

From this experience, the PROJIMO workers learned the importance of including the family - from the beginning - in the problem-solving process. They yielded to the mother's choice of the over-sized chair.

But Marcos was unhappy. He had fallen in love with the small chair, which he could move around by himself. It would be hard to take the small chair back, once the boy had tried it.

In the end, the team made a costly but caring decision. The family kept both chairs. Marcos was, of course, delighted.



Sometimes Simple Solutions Are More Appropriate than Complex Ones

Often a simple device can make as big a difference as a more complex one. And if the device is simple, the user can understand, make, adapt, and control it more easily. Mike Miles, a perceptive observer who worked in community-based rehabilitation in Pakistan for many years, tells a thought-provoking story, which I paraphrase below.

WHICH IS MORE APPROPRIATE? ... WHO IS MORE INDEPENDENT?

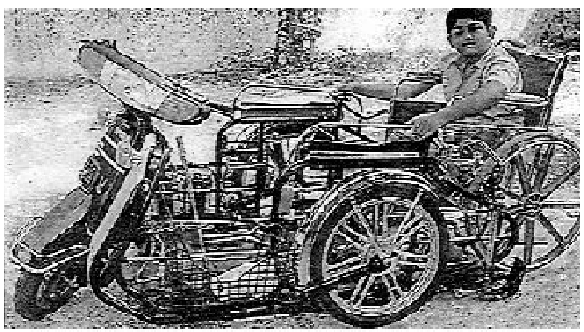
One time, in Europe, a man with paralyzed legs wanted to mail a registered letter at the Post Office. He drove his **specially adapted van** to the city center and parked in a disabled-parking spot near the Post Office. Using his van's **motorized lift**, he lowered himself in his wheelchair to the street. In his **battery-powered wheelchair** he zoomed to the front of the Post Office, only to discover that there were three steps he must go up to get inside. Unlike most Post Offices in Europe, there was **no ramp!** Cursing the insensitivity and unfairness of society, he turned his wheelchair around, roared back to his van, hoisted himself and his chair up into it on the lift, and angrily drove home - his letter unmailed.

At the same time, in far-away Pakistan, another man who also had both legs paralyzed wanted to mail a letter at the local Post Office. He hopped on his small **skate-board** and pushed himself quickly along the narrow streets.

He hitched a ride by holding onto the back of a horse-drawn cart. At last he reached the Post Office. To enter it, there were 10 steps and no ramp No worry! He scooted off the skate-board onto the first step. With his arms, he lifted himself on his backside from one step to the next, dragging his skate-board with him. When he reached the top step, he hopped back on his skate-board, rolled to the counter, and handed the letter up to the postal clerk. Thanking him, he turned around, rolled back to the steps, scooted down them on his backside, and rode his skate-board home - his mission fulfilled.

"Which of these 2 men is more independent?" asks Mike. **"Which of the mobility aids is more appropriate? Which society is more at ease with disability?"** ... Clearly, the answers depend on the local situation, cultural faotors, and the view point of the persons involved (as well as your own).

COMPLEX AND COSTLY



Developed by the Spastics Society of India, Madras

This motorcycle with two back wheels has been adapted with a ramp at the back so that the wheelchair rider can wheel up into it and drive while seated in his wheelchair.

SIMPLE AND CHEAP

Like this chi]d from India who cannot walk, children (and adults) all over the world use skate-boards, trollies, or make

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Nothing About Us Without Us
Developing Innovative Technologies
For, By and With Disabled Persons
by David Werner

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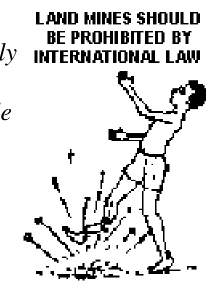
CHAPTER 29

Making Wheelchairs from Trash: Innovations in War-Torn Angola

Disabling Civilians as a Tactic of Low-Intensity Conflict



As a result of decades of civil war, ***ANGOLA****, a country in south-west Africa, has the highest rate in the world of people who have lost legs from land mines. Guerrilla troops, sponsored by the former apartheid (white rule) government of South Africa, have planted millions upon millions of mines. Those injured are mostly civilians, including women and children. Supplied by giant arms manufacturers in the North,* ***LAND MINES ARE DESIGNED TO CRIPPLE, NOT TO KILL.*** *This is part of the strategy of "low-intensity conflict." Leaving people seriously disabled puts a greater burden on families and on the nation than does killing people outright.*

National Rehab Centers in Angola - A Chronic Shortage of Materials

To do something for the vast numbers of civilians disabled by war, the government of Angola set up large rehabilitation centers in each province. These were intended to provide disabled persons with rehabilitation, assistive devices, and training in skills such as leather-work and carpentry, so they could soon return to their homes. But at the centers - as in the whole war-torn and economically devastated country - there was a chronic shortage of even basic materials such as leather, wood, nails, and glue. As a result, neither assistive equipment nor skills training were being provided. The rehab centers had become little more than long-term holding camps - sheltered workshops with no work.

To try to find a way out of this situation, in 1990 the Ministry of Social Affairs together with the *Development Workshop* (a Canadian non-profit group) organized a national workshop. One director and one disabled person from each of 15 provincial centers attended. The author (David Werner) and Kennett Westmacott were among the outside facilitators.

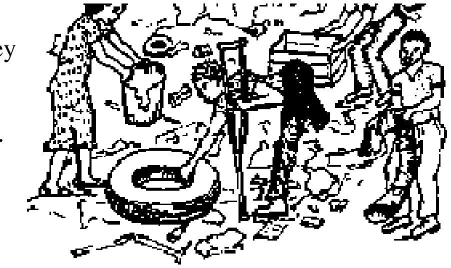
A National Workshop to Develop Equipment and Skills

THE GARBAGE DUMP AS A SOURCE OF SUPPLIES

The purpose of the workshop was to figure out *how to make assistive devices at low cost and with a scarcity of tools and materials*. Rather

than simply discuss how to make do with minimal resources, we decided to actually try to make needed aids and equipment for and with the disabled participants. if they themselves could master these skills, they could then not only help meet needs of other disabled persons, but they would have important work.

To find materials, we first made a trip to the city dump. We collected bits of wire, old plastic buckets, car tires, inner tubes, and bits of metal. About the only wood available was from broken packing crates left over from international aid shipments. Also, there were branches that could be cut from the few remaining ornamental trees.



The garbage dump provided a wide variety of useful materials.

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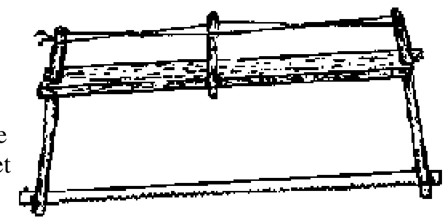
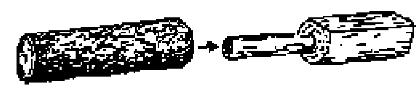
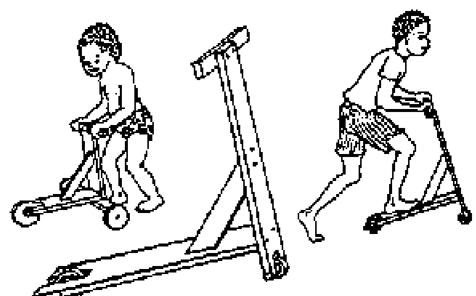
STARTING WITH BARE HANDS AND SHARP EYES

To start off the workshop, Kennett showed the group how to make a saw by filing teeth into the steel strapping from old packing crates. The blade is stretched between a frame made from sticks, and tightened by twisting a wire.

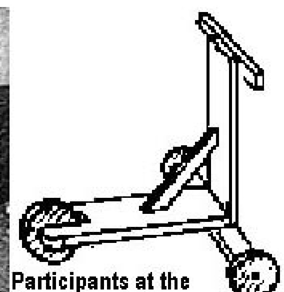




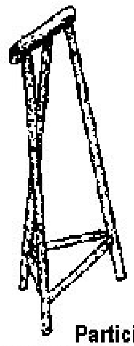


Familyies and street children are very creative in making equipment for moving from place to place more easily.

To get ideas for building things from scrap, we went into the streets and watched children playing with their homemade scooters, pushcarts, and baby carriages. The wheels of these were made of wood, or with large bearings from junked or bombed trucks. The ingenuity of the street children, inventing playthings out of anything at hand, was an inspiration and challenge to all.



Participants at the Angola workshop cut small wheels from logs. The thicker the wheels, the more weight they are likely to support without breaking.



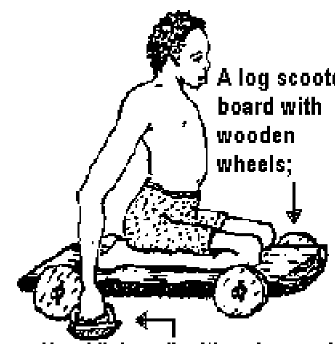

Participants in the workshop make a three-legged walking stick from tree limbs.

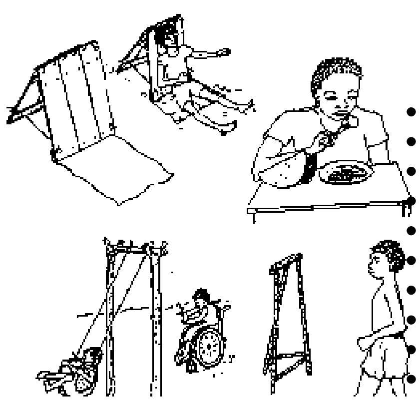
LEARNING TO MAKE ASSISTIVE DEVICES.

During the 2-week workshop, the group managed to make a wide variety of assistive devices. These were mostly created to meet the expressed needs of the disabled participants.

For example, one participant, named **KOFI**, had paralysis in the lower body, with hip and knee contractures. He scooted about on his backside using his hands. He wanted some way to move faster and easier. So the group designed and made for him:

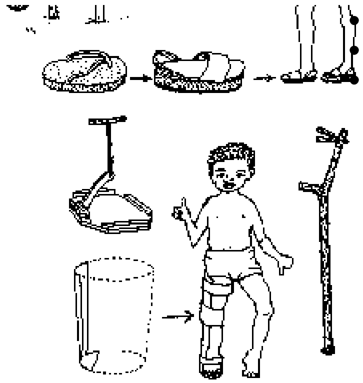
- A log scooter-board with wooden wheels;
- Hand "shoes" with soles made from old tires.





To meet a wider range of disability needs, the workshop invited disabled adults and children in the local community (on the outskirts of Luanda) to visit. Devices that the workshop participants created to meet the needs of these visitors included:

- A foldable sitting frame for a disabled child
- Artificial legs (both rustic and prefabricated) (see page 180)
- An arm rocker, so that a person with a paralyzed arm can feed herself
- A special seat with a table made of foam plastic (see page 179), and toys for a child with cerebral palsy
- An enclosed swing made from an old tire, turned inside out (see page 57)
- A 3-legged walking stick made from tree branches (page 174)
- Ramps for wheelchair access and exercise (see page 230)
- An orthopedic lift for a sandal or shoe, made from old foam-rubber "thongs"
- Under-arm and elbow crutches, made from tree branches
- A tray for disabled persons to transport drinks without spilling them (see Chapter 22, page 135)



- Wheels, pieced together from old wooden packing crates (see the next two pages)
- A wooden wheelchair, made from packing crates (see page 178)
- Leg braces made from an old plastic bucket, especially designed for a little girl with severe bowing of the knees

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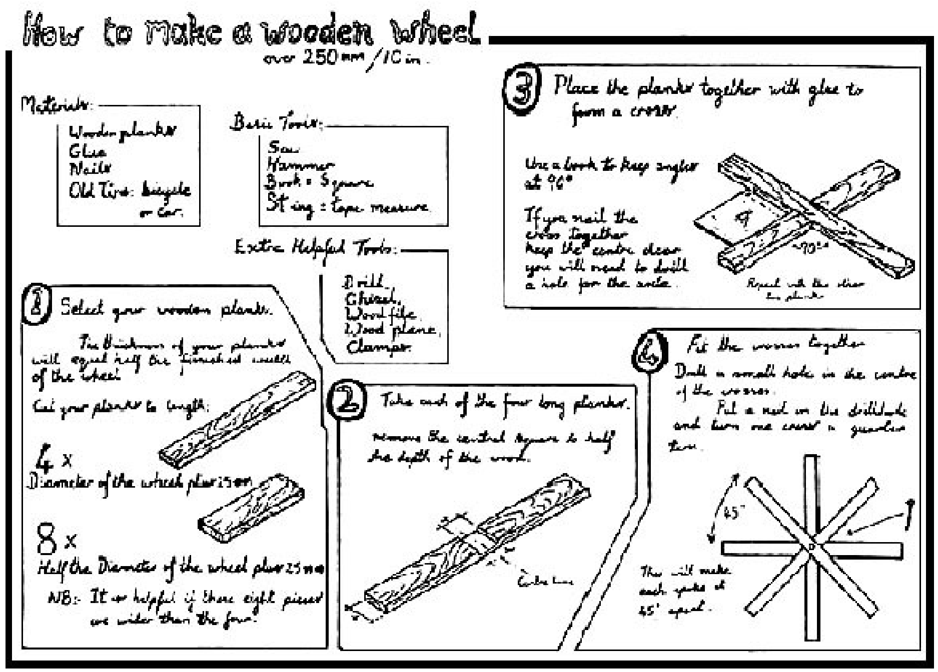
HOW TO MAKE A WOODEN WHEEL



Materials: Wooden planks, Glue, Nails and Old Tire(bicycle or car).

Basic Tools: Saw, Hammer, Book (square), Sting (tape measure).

Extra Helpful Tools: Drill, Chisel, Wood file, Wood plane, Clamps.

1. Select your wooden planks.

The thickness of your planks will equal half the finished width of the wheel.
Cut your planks to length:
4 x (Diameter of the wheel plus 25 mm).
8 x (Half the diameter of the wheel plus 25 mm).
NB: It is helpful if these eight pieces are wider than the four.

2. Take each of the four long planks.
Remove the central square to half the depth of the wood.

3. Place the planks together with glue to form a cross.
Use a book to keep angles at 90 degrees.
If you nail the cross together, keep the centre clear.
You will need to drill a hole for the axle.
Repeat with the other two planks.

4. Fit the crosses together.
Drill a small hole in the centre of the crosses.
Put a nail in the drillhole and turn one cross a quarter turn.
This will make each spoke at 45 degrees apart.

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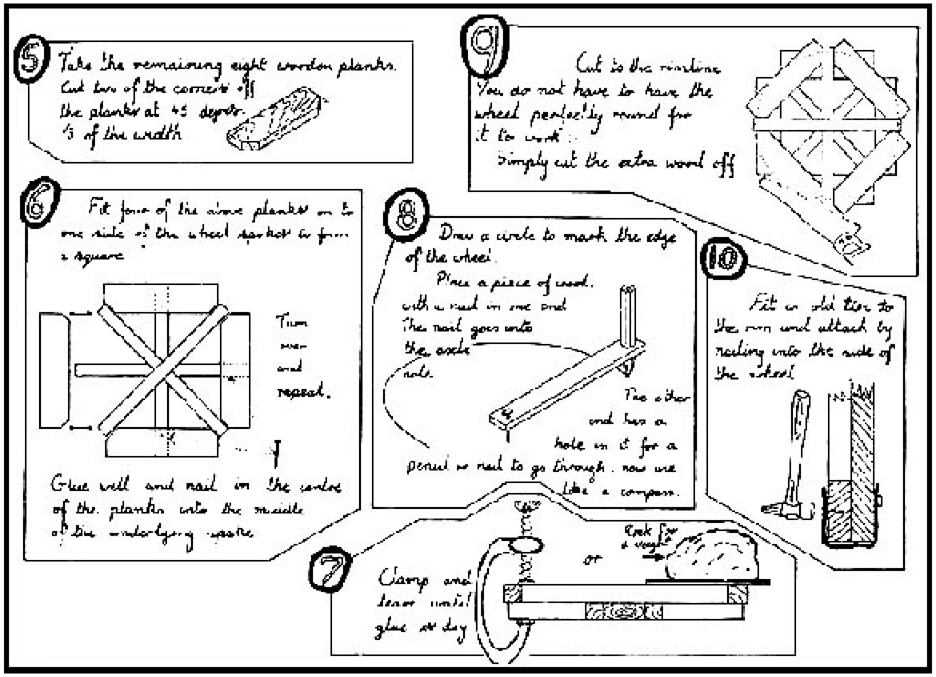

5. Take the remaining eight wooden planks.
Cut two of the corners off the planks at 45 degrees, one third of the width.

6. Fit four of the above planks on to one side of the wheel spokes to form a square.
   Glue well and nail in the centre of the planks into the middle of the underlying spoke.
   Turn over and repeat.

7. Clamp (or rock for a weight) and leave until glue is dry.

8. Draw a circle to mark the edge of the wheel.
   Place a piece of wood with a nail in one end.
   The nail goes into the axle hole.
   The other end has a hole in it for a pencil or nail to go through, now use like a compass.

9. Cut to the rimline.
   You do not have to have the wheel perfectly round for it to work: -
   Simply cut the extra wood off.

10. Fit an old tire to the rim and attach by nailing into the side of the wheel.

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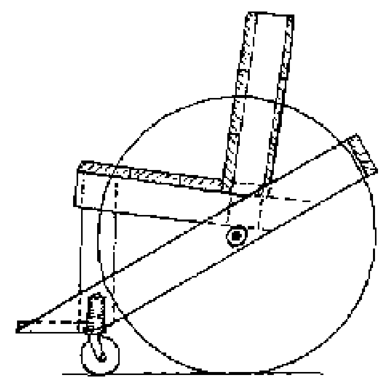
A WHEELCHAIR FOR MOSES

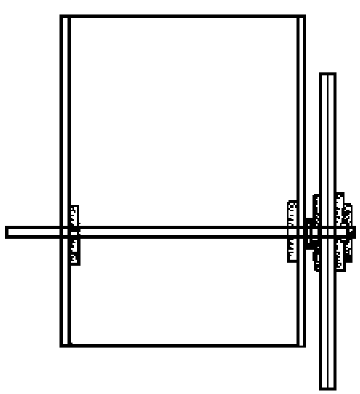
*One of the workshop participants, **MOSES**, had been disabled by a land mine. He walked with great difficulty, supporting his weight with a pole. Moses very much wanted a wheelchair. At first this seemed virtually impossible, given the !ack of key materials, especially wheels. But the group was determined to try. The best building material they had was poor-quality, half-inch-thick planks they had scavenged from o!d packing crates.*



With suggestions from Moses and others, the group drew an initial design for a wooden wheelchair. When the final design was agreed upon, the drawing was enlarged to full size on packing paper, so that the different pieces could be traced onto suitable pieces of wood.

Kennett Westmacott had already taught the participants how to piece together large wooden wheels, using scrap wood from the packing crates. The group put together the wheels and the entire chair using nails pulled out of the packing crates and then hammered straight.

The outer edge of the big wheels were covered with strips of rubber cut from old car tires.



Instruction sheets for making the large wheels were provided by Kennett, and are reproduced (with minor modifications) on the two pages before this one.

With 4 small ball-bearings they had found, they mounted the back wheels on an axle made from a length of 3/4 inch reinforcing rod. The bearings were force-fitted (with a hammer) into inset-holes chiseled into square pieces of Angolan hardwood, found by the scavengers.

For the small front wheels of the chair, participants had hoped to use large truck bearings, similar to those that the street children use for scooters. But the bearings proved difficult to find. At last, someone located a couple of old plastic caster wheels, so these were used. No welding was needed for any part of the wheelchair.

By dividing into small groups that worked at the same time on different parts of the project, the chair was completed in 4 days. It was remarkably sturdy and functional. Moses, who had played a key role in building his chair, loved it. As a last addition, he built a small box on the outer edge of the wooden footrest to hold the front end of his walking stick.

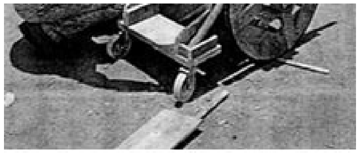


Photo by Alain Cane, Development Workshop

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AN OUTCOME: MUTUAL RESPECT GAINED BY DIRECTORS AND DISABLED PARTICIPANTS

By working together, the disabled participants and the directors of the rehabilitation centers learned to respect each other's different, but equally important, skills.

Perhaps the most worthwhile part of the workshop was the understanding and respect that grew between the members. At the start, the directors of the rehab centers were hesitant to take part in the manual work. They were reluctant to put themselves on an equal footing with the disabled participants, many of whom were unschooled villagers. The disabled persons, in turn, seemed unsure of themselves and uncomfortable when working alongside the administrators.

However, in the process of working and problem-solving together, everyone began to relax and to appreciate each other's skills. In some areas, such as measuring and interpreting graphic designs, the officials were more able. But in the use of tools and building of devices, many of the people with disabilities were obviously more capable. Each group learned from the other. By the end of the workshop, a strong sense of camaraderie had developed, and everyone seemed more confident.

THE BEGINNING OF AN ORGANIZATION OF DISABLED PEOPLE IN ANGOLA

Another important outcome of the workshop was unplanned. The disabled participants, who came from many parts of the country, recognized that they had a lot of common concerns. They also realized that, by working together to try to solve one another's problems, they could accomplish a lot.

As a result, they began to talk about forming some kind of a network, or organization. This was significant because, at that time, there was no association of disabled people in Angola.

However, there was a major barrier to forming such an organization. At that time, because of all the terrorism and social unrest, the government prohibited all popular organizations, even at the community level. Fortunately, a high official in the Ministry of Social Affairs attended the closing ceremony of the workshop. The disabled participants presented to her their need and desire to form a national organization of disabled people. The official promised to arrange permission for this. We learned later that permission was granted, and an Angolan branch of *Disabled People's International* has now become a reality.

Participants made a child's seat from scraps of wood and foam plastic. They put a raised border on the table to help keep toys from falling off.

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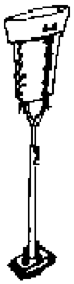
NEED TO PREPARE THE STUMP BEFORE FITTING AN ARTIFICIAL LEG

One of the workshop participants had lost his leg due to a land mine. The group made plans to create a make-shift limb out of bamboo or PVC (plastic pipe) for him. (Designs and instructions for both types of limbs can be found in the book, *Disabled Village Children*.)



However, when a leg-making team from the *Swedish Red Cross* visited the workshop, they brought **a fully adjustable, low-cost prosthesis** (artificial limb) created from local materials. Both the socket and the length of the leg could be quickly modified to fit different persons.

A bamboo leg made at PROJIMO, in Mexico (see chapter 18).

This limb had a laced leather socket attached to a thin steel tube. The length of the tube could be adjusted by a simple telescoping mechanism.

The Red Cross team attempted to fit the limb to the amputee in the workshop. However, they ran into a problem. In the 3 years since his amputation, the man had developed contractures and muscle weakness in the hip. Also, the stump was swollen and flabby. All of this made accurate fitting and safe weight-bearing on the adjustable limb impossible.

After waiting years for a leg from the government, this man made his own.

From this failed attempt, participants realized that an artificial limb is only a part of the rehabilitative need of an amputee. In the period between losing the limb and getting a prosthesis, it is important that the person:

Do exercises to maintain strength and prevent contractures, and
Keep the stump bandaged, to prevent swelling and puffiness.

An instruction sheet on stretching and strengthening exercises (partly adapted from the book, *Disabled Village Children*) was developed by the workshop facilitators. It was given to all participants so that they could work with other amputees in the different centers. That way, when there was an opportunity to get an artificial limb, the chances for successful fitting and use would be greater.

THE ENORMOUS NEED FOR ARTIFICIAL LIMBS - AND AN END TO VIOLENCE

Everyone agreed that there was a **great need for dozens of small, decentralized limbmaking workshops** in the provinces, preferably with disabled persons as technicians. Today, Angola has tens of thousands of amputees waiting for limbs. Although the war has more-or-less ended, hundreds of thousands of land mines still cover the landscape. So thousands of men, women, and children will continue to have their legs blown off.

Workshop participants realized that **the only long-term answer is to outlaw land mines by international law**. But that would be just a beginning. Corporate rule, and the power of the multinational arms industry must also be confronted, as well as the unfair distribution of wealth and power that leads to so much poverty, crime, internal strife, and institutionalized violence. **Disabled people need to join with other marginalized and disadvantaged groups in the struggle for a kinder, fairer world**. (See the book, *Questioning the Solution* for more on the politics of health and disability. See page 344.)

Learning From and Admitting Our Mistakes

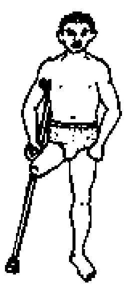
The illustrated instruction sheet shown below was developed at the Angola workshop. Copies were made for participants to take back to their centers, to help persons who had lost a leg maintain the movement and strength needed to successfully use an artificial leg, if and when they got one. (Another information sheet gave instructions on how to bandage the stump, to prevent the swelling and flabbiness that make it hard to fit a limb.)

Unfortunately, the original exercise sheet, although it was designed by rehabilitation professionals, had some problems. The mistakes were pointed out to me, years later, by Ann Hallum, an outstanding physical therapist who reviewed the manuscript of this book.

Question: *Some of the exercises shown below should usually be done differently, or not be done at all. Do you know which ones? And why?*

Answer: **CAUTION with exercises 1, 3, and 4.**

Exercises 1, 3, and 4 should be done differently. **They can lead to muscle imbalances and contractures that make walking with an artificial limb much more difficult.**



After the loss of a leg, the person tends to hold his stump lifted up and out, like this.

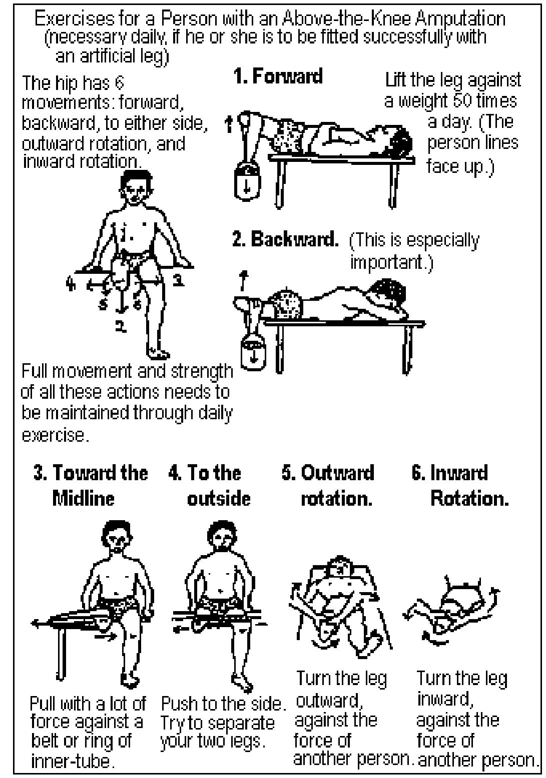
By doing this, he uses and strengthens the muscles that bend the stump up and out, more than those that bend it in and back. This results in a muscle imbalance that can lead to contractures that will interfere with walking.

Therefore, it is best to **do exercises to strengthen the weaker muscles that can help combat contractures. And stretch (but do not strengthen) muscles that contribute to contractures.**

To combat contractures, Exercise 1 should be done to stretch, not strengthen. Exercises 3 and 4 should be done lying down (to reduce flexion contractures of thigh). And if you do exercise 3, avoid opening the thigh to the side past mid-line.

A corrected version of this exercise sheet is shown on the next page ... Live and learn!

AN INSTRUCTION SHEET WITH FAULTY ADVICE:



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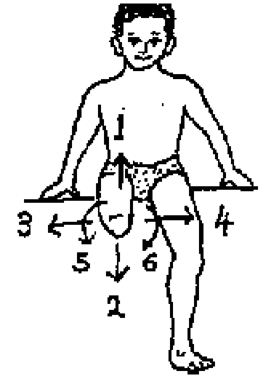
This is the **corrected version of the Exercise Sheet** shown on the preceding page.

Exercises for a Person with an Above-the-Knee Amputation

(necessary daily, if he or she is to be fitted successfully with an artificial leg)

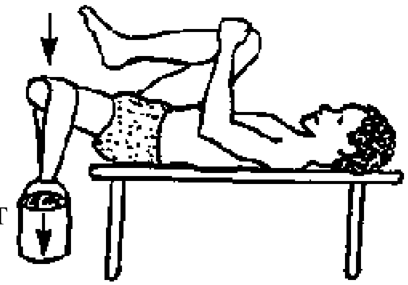
The hip has 6 movements:

1) forward
2) backward
3, 4) to either side
5) outward rotation,
6) inward rotation.



Full movement and strength of all these actions (except the first) need to be maintained through daily exercise.

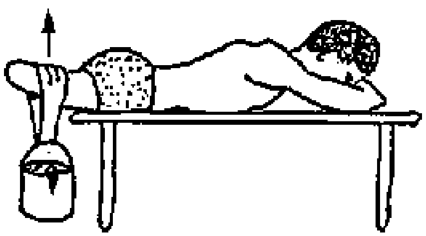
1. Forward Movement*



CAUTION: Use this exercise to stretch the muscles that flex the thigh, not to strengthen them. Don't lift against the weight; let it pull the thigh backward. Bend the other knee up, to prevent the lower back from bending instead of stretching the hip. It is usually best to avoid exercises that strengthen forward-lifting of the stump (hip flexion).

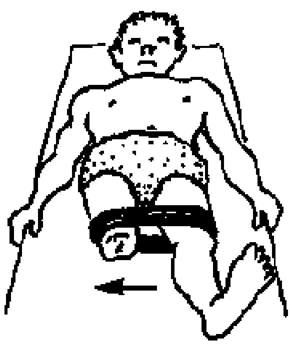
As a general rule: DO THIS EXERCISE. ONLY TO STRETCH THE STUMP DOWN. DO NOT LIFT IT UP.

2. Backward
(This is especially important for being able to walk with a full range of motion.)



Lift against weight 50 times a day. (The person lies face-down.)

3. To the outside

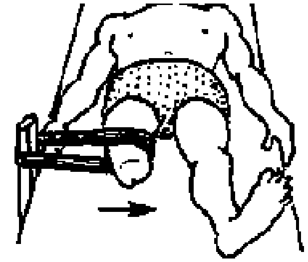


Push to the side, trying to separate your legs.

(But do this so that the stump stays in the mid-line, and does not sving out to the side.)

4. Toward the mid-line

Pull with a lot of force against a belt, or a ring of inner-tube.



5. Outward rotation

Turn the leg outward, against the force of another person.

6. Inward rotation

Turn the leg inward, against the force of another person.

***Note: With Exercise 1, it is important to let the hanging weight stretch the hip down. Do not try to lift the stump.** This will help avoid hip flexion contractures (inability to straighten the hip) that would make walking more difficult. For a similar reason, **do Exercises 3, 4, 5, and 6 lying down.**

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Nothing About Us Without Us
Developing Innovative Technologies
For, By and With Disabled Persons
by David Werner

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CHAPTER 30

Evolution of the Whirlwind Wheelchair

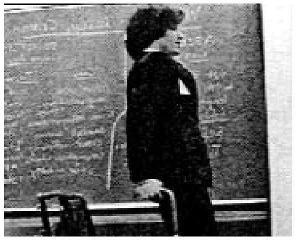
The Best wheelchair Designers? Wheelchair Riders!

Everest and Jennings *is the brand name of the world's largest wheelchair manufacturer. Many people do not realize that the original designer and founder of this global wheelchair business was disabled and rode a wheelchair himself.* ***The original "E&J" wheelchair - which was a breakthrough in its day - grew out of a disabled person's creative response to an unmet personal need.***

But as E&J Industries grew, the company became more interested in mass-production than in innovation. Fortunately, however, other disabled persons have continued to advance the state of the art. ***Like Herbert Everest, many of the most innovative wheelchair designers in the past 20 years have themselves been wheelchair riders.***

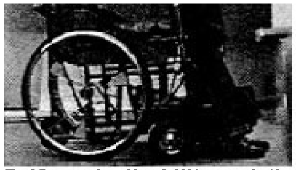
Ralf Hotchkiss teaches disabled wheelchair builders at PROJIMO.

RALF HOTCHKISS AND THE WHIRLWIND



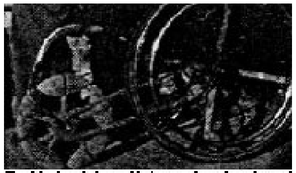
One of the world's most caring and creative wheelchair designers and builders is Ralf Hotchkiss, who lives in California, USA. Ralf became paraplegic (paralyzed from his chest down) from a motorcycle crash when he was a teenager. Since then, Ralf trained as a mechanical engineer, and has designed and built a wide range of innovative wheelchairs and other equipment.

When Ralf first decided to build a **4-wheel drive wheelchair**, he had a hard time figuring a way to transfer power from the large back wheels to the small front wheels. The obvious solution was to use bicycle chains. But for this, the front wheels would need to not swivel (pivot) to make turns, as do caster wheels of most wheelchairs.



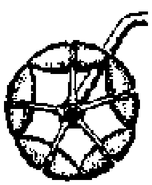
Ralf's early disability-assistive inventions included a standing wheelchair that can lift the rider from sitting to standing.

Furthermore, caster wheels need to be fairly small to avoid bumping the footrests when they pivot. But, to move easily on rough ground, Ralf's front wheels needed to be relatively large. What to do???



Ralf, in his all-terrain 4-wheel drive wheelchair. A bicycle chain transfers power from the back wheel to the front.

The solution, Ralf explains, came from the Bible: the so-called **Ezekiel Wheel, a circle of small wheels that together form a larger wheel.** With this idea, Ralf created a front wheel made of a series of small rubber cones, positioned in a circle around the central hub. Each cone is mounted on its own ball bearings, so it can roll sideways, while the wheel as a whole rolls forward. This combination of several small wheels within a bigger one gives a multi-directional roll similar to that of a caster wheel. However, the forward direction of the main wheel is fixed and it does not pivot. This is what Ralf needed for his 4-wheel drive.



Ralfs "Ezekiel wheel." The small rollers roll sideways. The main wheel rolls forward. This gives a multi-directional caster effect, without swiveling.

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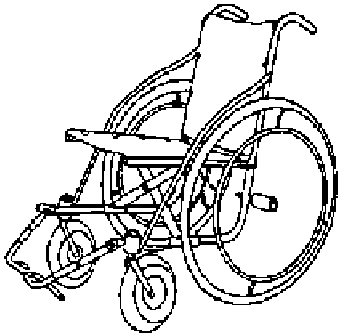
Low-Cost, High-Quality Wheelchairs Made by Third World Riders

Although Ralf's 4-wheel drive wheelchair worked well, it never became popular. Building it was too costly and time consuming. Just the front wheels used 24 bearings and 20 individually vulcanized cones.

Ralf's interest turned to developing low-cost wheelchairs for the Third World, using "appropriate technology." His incentive was sparked on a visit to Nicaragua in 1980, shortly after the Sandinistas overthrew the Somoza dictatorship. A group of young Sandinistas who had been spinal-cord injured during the war had formed a grassroots group called **Organization of Disabled Revolutionaries (ORD)**. They had so much trouble getting wheelchairs that four of their members were sharing a single wheelchair. Most wheelchairs in Nicaragua were imported from the USA. With the stiffening US embargo, both chairs and spare parts were very hard to find. The ORD members had difficulty reintegrating into society and finding work because they lacked mobility. Some, whose wheelchairs had broken down, had gone back to dragging themselves about in their homes, unable to leave.

For these reasons, the Disabled Revolutionaries set up a small wheelchair repair shop. But they ran into problems. Commercial imported chairs, such as *E&Js*, have poor-quality bearings which wear out quickly in a rough, dusty environment. Because they are not a standard size, they could only be replaced with over-priced bearings purchased from the original manufacturer. The cost was prohibitive. In places like Nicaragua, where bearings of any kind are often not available, wheelchair maintenance becomes extremely difficult.

Clearly, such dependence on expensive, hard-to-maintain, imported chairs increased people's handicaps. Ralf worked with ORD to design a low-cost wheelchair that could be built from local materials by modestly-skilled disabled workers. The result was the *Torbellino*, or Whirlwind Wheelchair. Within a year, ORD was operating a mini-factory in which a team of disabled persons built this home-grown design.



THE WHIRLWIND WHEELCHAIR is relatively easy to build in a modestly-equipped shop. Yet its quality is excellent. As a wheelchair rider himself, Ralf appreciates the need for a light-weight, compact, easy-rolling, trouble-free chair. The design of the Whirlwind is simple and stream-lined, but a great deal of skillful engineering has gone into it.

The frame of the chair is made from electric-conduit steel tubing, available in building supply stores around the world. The back wheels are bicycle wheels. The bearings (of the early model) are standard high-speed bearings used in small electric machinery. Used bearings can often be obtained at very low cost in electrical repair shops. These are

finely made bearings for high speed use. Even secondhand ones, used in a wheelchair, will long outlast commercial wheelchair bearings.

The beauty of the Whirlwind is that it is made in small community shops by disabled people who recognize the need for a chair that is adapted to the needs of the individual rider.

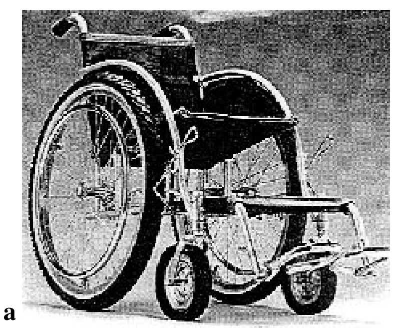
These wheelchairs tend to be custom-built or adapted. In the process, new design opportunities arise, and the chairs come closer to matching the varied needs of their users.

The long-term vision:
WHEELCHAIRS FOR ALL WHO NEED THEM

Since helping ORD in Nicaragua, Ralf has traveled around the world, facilitating workshops and helping groups of disabled persons begin to produce appropriate wheelchairs. One of the first groups he worked with was PROJIMO, in the mountains of Western Mexico. Over the years, Ralf has led workshops and worked with disabled wheelchair builders in 30 countries in Latin America, Africa, Asia, and Russia.

Ralf calculates that, **of the 20 million people in the Third World today who need wheelchairs, fewer than one percent have them**. He dreams of the day when all who need a wheelchair will have a chair fully suited to their needs. To this end, he and his friend, Peter Pfaelzer at San Francisco State University, formed **Wheeled Mobility**, a small non-profit organization which is rapidly turning into an international network of wheelchair builders and designers. **If there are ever to be enough wheelchairs - chairs that are truly liberating to their riders - production must be decentralized and the building process must be demystified, with users leading the process.**

RECENT WHIRLWIND INNOVATIONS



The basic design of the Whirlwind keeps evolving. Not only has Ralf continued to design and test new features himself, but he has gathered new ideas from groups of disabled persons around the world who are building local variations of the Whirlwind.

It should be noted that many of these new features were developed in collaboration with disabled persons who expressed difficulties with the existing design or who wanted some particular modification.

In this book, we do not give detailed instructions for making the Whirlwind wheelchair. A brief description can be found in the book, *Disabled Village Children.* Very detailed instructions - including suggestions for setting up and stocking a shop - are in Ralf's fine handbook, *Independence Through Mobility* (see page 343).

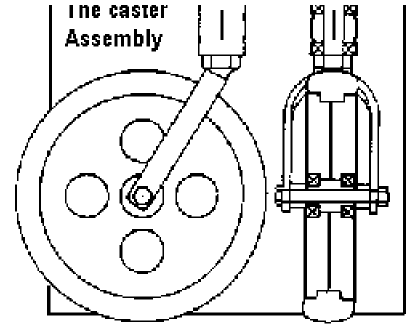
For years, Ralf has been revising and updating this book, but new ideas come so fast that it is a never-ending process. **In this chapter we will give a preview of just a few of the most innovative modifications and improvements of the Whirlwind chair.** While developed primarily for the Whirlwind, most of these innovations can be adapted to other models, or even to commercial wheelchairs.

1. *Front Wheels and Tires*

The front caster wheels and tires of the Whirlwind have presented some big design challenges. Caster wheels are complex and costly. They

require two sets of bearings, one vertical and one horizontal, so that the wheels can swivel, as well as rotate. (The swivel is what allows the chair to make turns.)

The basic front-caster design and the wheel forks remain much the same as in Ralf's original book (and in *Disabled Village Children*). A new design for bearings is discussed under entry #2. Here, we look at innovations in wheels and tires.



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FRONT WHEELS AND TIRES TO SUIT DIFFICULT TERRAIN: A THORNY PROBLEM

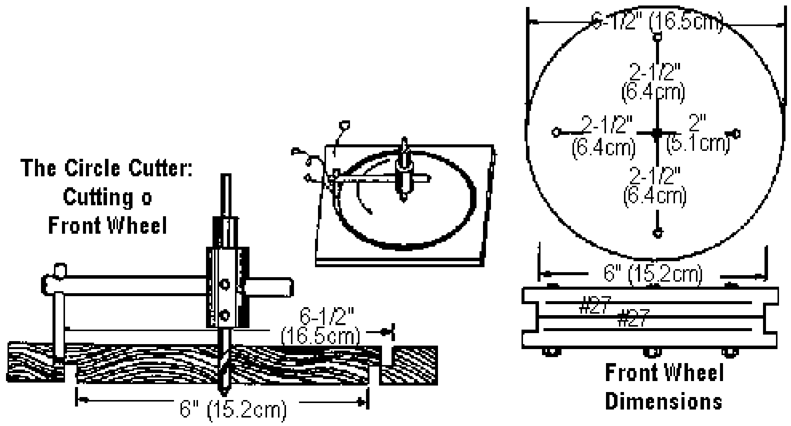
Most modern commercial wheelchairs now come with tiny, hard, rubber or plastic front wheels. These are good for gliding over hospital floors or smooth, paved streets. But they function poorly on the rough, sandy paths of villages, or on the pitted, irregular roads of many Third World cities. For difficult or sandy terrain, front wheels need to be relatively big (6 to 9 inches in diameter) and wide (1+1/2 inches or more).

Drawing from "Independence Through Mobility" by Ralf Hotchkiss.

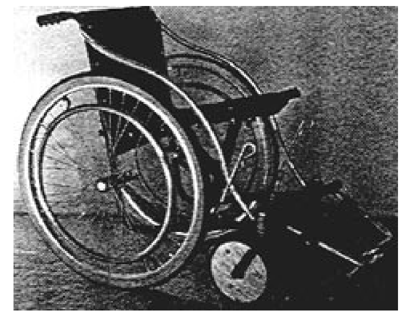
Pneumatic tires (filled with air, under pressure) are light-weight, and on rough terrain they give a much smoother ride (which may add to the life of the wheelchair - and the rider).

But air-filled tires also have short-comings. On rocky or thorny paths they puncture easily and often need to be patched and pumped up. Also, pneumatic tires that fit small caster wheels tend to be outrageously expensive. And, in many countries, they are simply not available. In the original version of *Independence Through Mobility*, Ralf gave an address in China where pneumatic tires and tubes can be bought in large quantities at relatively low cost. But this is hardly an ideal solution for equipment designed to use local, easily obtained materials.

The wheels have presented another problem. In the early Whirlwind design, Ralf recommended making front wheels from two discs of hard wood, glued together, with their grain crossing (at right angles) to prevent splitting. The photos of the Whirlwind, below and on p.195, show the wooden wheels.



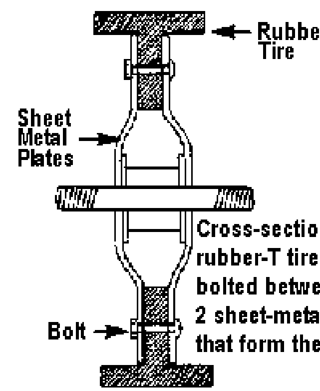
Designs from Independent Through Mobility, for cutting and assembling the wooden front wheels.



These wooden wheels were tried at PROJIMO in Mexico, but many users found them unsatisfactory. In spite of attempts to waterproof them with heavy varnish or epoxy finish, in the mud and rain they soon rotted and cracked. Riders in other countries reported similar problems. Another problem was that some people who wanted to purchase a wheelchair thought wooden wheels were primitive and ugly. They insisted on having "modern" wheels, even if more costly. Whatever the reasons, such preferences must be taken into account.

Molded aluminum wheels were another alternative considered by Ralf. Workshops in Brazil and Bangladesh cast and lathe-turn their own aluminum wheels. But for most small production centers, this is impractical. The set-up costs are prohibitive.

A rubber T tire, clamped between metal plates. A new design came from RESCU, a production center in Zimbabwe where disabled workers build assistive equipment, including the Whirlwind wheelchair. The front wheels consist of **two round sheet-metal plates which grip a molded rubber tire.**



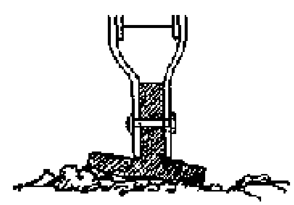
Cross-section of rubber-T tire, bolted between 2 sheet-metal disks that form the wheel.

A modified Zimbabwe wheel, made at PROJIMO.

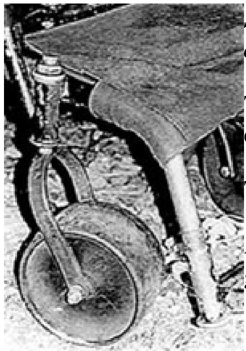
The tire, in cross section, is T-shaped. The center-arm of the T projects inward, and is firmly held with bolts between the 2 metal plates. The tire is vulcanized (heat-molded) in a specially lathe-turned steel mold. Once the mold is made, any shop that retreads car tires can produce these T-tires in small or large quantities at a relatively low cost.

The wheel is made by cutting two round disks of sheet metal. The disks must be widely separated at the center to hold the hub firmly, and shaped so they can grip the T-tire. A dye of lathe-turned steel is needed to hammer, press or spin the disks into shape.

The advantage of this Zimbabwe wheel is that, after a (fairly costly) initial investment for the molds and dyes, the production cost can be quite low. The tire, made of the same rubber as a car tire, is nearly indestructible. Its broad, T-shaped base has almost the same flexibility and springiness as a pneumatic tire. But it never punctures. Wider tires can be made for sand, to prevent sinking in.



Problem: In Zimbabwe, the wheel was made of fairly thick sheet metal, pressed into shape in a large metal-press delivering tons of weight. In redesigning the wheel for smaller shops without such massive presses, Ralf began to experiment with a thinner grade of sheet-metal that could be hammered into shape when the metal disk was clamped over a dye. The PROJIMO wheel-chair builders tried making these wheels. At first, they appeared to work well. But, after repeated bumps into rocks and curbs, the metal disks bent and finally collapsed. The PROJIMO team tried using thicker sheet-metal, but it was too difficult to hammer into shape. Groups experimenting in other countries ran into similar problems.



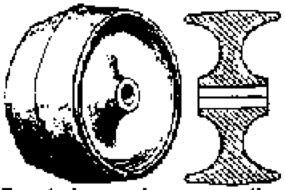
The all-rubber wheel and tire.

Solution: **An all-rubber wheel and tire**. After exploring many possibilities, Ralf found a simple solution. *Do away with the sheet-metal disks and* ***mold the entire tire and wheel out of vulcanized rubber, as a single unit.***

The central part of the wheel is cast thick enough to make it inflexible. The wide outer-edge that rolls against the ground is thin enough to provide a spongy flexibility.

The wide center-part of the wheel is molded to grip the hub. A flange, welded to the hub, is bolted to the wheel.

A big advantage to this all-rubber wheel is that it bends easily, to ride smoothly over irregular terrain. These simplified wheels show great promise. Eventually, they may be used for both front and rear wheels of **all-terrain wheelchairs.**



Front view and cross-section of the all-rubber wheel.

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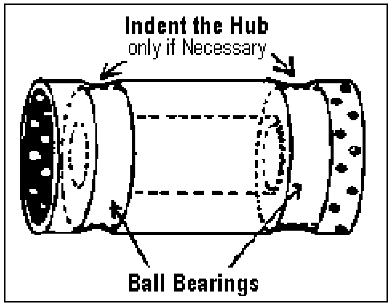
2. *Bearings*

Among the biggest problems with many wheelchairs are the bearings. Commercial chairs use off-size ball bearings of relatively poor quality. They soon wear out, making the wheels wobbly and hard to push. Since the bearings are not a common size, often they cannot be replaced locally, but must be obtained at high cost from the wheelchair supplier or the manufacturer. Where chairs are imported, this may be very difficult or impossible. The Third World is littered with carcasses of fancy imported chairs whose bearings wore out.

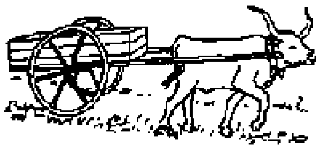
For this reason, the original Whirlwind design uses local, widely available bearings. If dust or dirt get into the bearings, it can ruin them. So, sealed bearings are recommended. Though more costly, the user saves money in the long run. **Second-hand high-speed, sealed bearings** of a workable size (5/8 inch inside diameter, 1+3/8 inch outside diameter - or 15 x 35 mm metric equivalent) can often be found in junk yards (in starter motors of old cars) or in small motor or power tool repair shops. (For more details, see *Independence Through Mobility*.)

Problem: When PROJIMO began making wheelchairs, it could get all the second-hand bearings it needed free or at low cost from friendly repair shop owners in the closest cities. But as the program produced more and more chairs, the repair shops ran out of second-hand bearings. PROJIMO had to buy new bearings, which were very expensive. The 12 sets of bearings needed for a wheelchair cost as much as all the remaining materials! This pushed up the price so much that many poor families could not afford it. Many other wheelchair-making shops have had a similar experience.

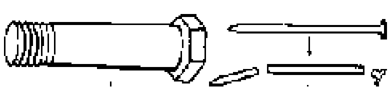


Whirlwind hub design showing fit of bearings.(from *Independence Through Mobility*, p.82)

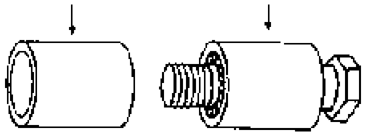
Solution: An idea to solve this problem came from India. On a visit there, Ralf Hotchkiss inspected the huge wheels of the traditional ox carts. They used an ancient form of **rod bearing, or "needle bearings."** The wheels rolled on a series of metal rods which fit snugly between the iron hub and the axle.



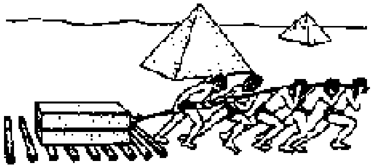
Old Indian ox carts use rod bearings.



Ralf experimented with hubs that, instead of ball bearings, use metal rods that roll between the axle and the hub tube. But the rods sometimes jammed in the hub.



An old mountain farmer in the eastern USA solved this problem by showing Ralf that thinner rods in a longer hub do not jam. Ralf now uses carpenter's nails with their heads cut off. The nails form a circle of rollers between the axle bolt and metal hub tube.



Rod bearings were used to move the rocks to build the pyramids in Egypt.

Ralf has tested the ease with which the wheels turn compared to ball bearings, and finds them equal. The cost of materials for rod bearings is a fraction of that of commercial ball bearings. Rod bearings require more work, but durability tests indicate that they last many times longer. (Whereas ball bearings bear the weight of chair and rider on a tiny point on each tiny ball, with rods, the weight - and wear - is spread over the full length of the rods.)

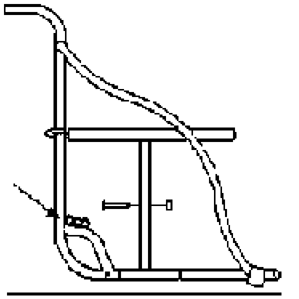
These new (though ancient) bearings show great promise. Hopefully they will contribute toward providing high-quality, long-lasting wheelchairs to many of the millions of people who need them, at a cost more within their reach.

Ralf in his wheelchair with rod (nail) bearings.

3. *Folding Mechanism, with Adjustable Chair Width*

Different adjustments on wheelchairs. People who ride wheelchairs come in all shapes and sizes. So should wheelchairs. Many commercial chairs - although the basic models are standardized - come with adjustable footrests, armrests, and alternative positions for the rear hubs.

Hub position. By changing the up-and-down position of the hubs in relation to the chair, the height and tilt of the seat can be changed. By changing the front-to-back position of the hubs, the balance of the chair can be changed. For example, a person without legs may need the rear hubs mounted farther back to avoid falling over backwards when going up-hill.



A series of axle tubes on the frame of the Whirlwind permits the hub position to be adjusted. (Hotchkiss)

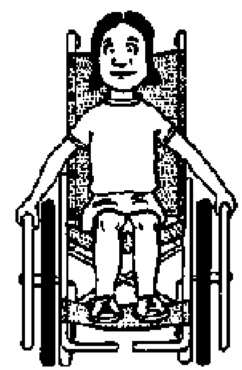
An advantage to producing wheelchairs in small, community-based shops is that often they can be custom-made. Rather than adding a lot of mechanisms for adjustments to meet different user's needs (which add to both weight and cost), each chair can be personalized from the start, to meet the specific needs of the intended user. If the wheelchair makers are also wheelchair riders, they are likely to be more aware of and responsive to those needs, and to include the user in the planning and design process.

Nevertheless, even in a small community shop, some amount of standardization can make production quicker, easier, and cheaper. It helps to have a selection of ready-made chairs available when they are needed. That way the person can try different chairs and pick the one that comes closest to meeting her or his needs. Last minute adjustments (or even more substantial changes) can then be made according to the individual's requirements.

Goodness of fit - in terms of size, width, seat angle, angle and height of back, need for armrests, position of footrests, etc. - is essential. Decisions need to be made *with* the user, *not for* her, allowing enough time to test different alternatives and make well-informed decisions.

ADJUSTABLE FEATURES OF THE WHIRLWIND. Although the Whirlwind has a basic (if evolving) design, it can be built and modified in different ways for different users. The **height of the footrests** can be easily adjusted by the user. Also, in response to his own need and that of others with spastic ankles, a PROJIMO wheelchair builder, Martín Pérez (see Chapters 37 and 39), has designed a simple way to **adjust the sideways angle of the footrests.**

One of the greatest needs for adjustability in wheelchairs is the **width of the seat**, and thereby the **width of the whole chair**. Correct width is important for the stability and comfort of the rider, and for her ease in pushing the chair. A new design for easy adjustment of chair width has been developed, together with a new mechanism for folding the chair.



A chair that is too wide is hard to push. (From *Independence Through Mobility*, page 26)

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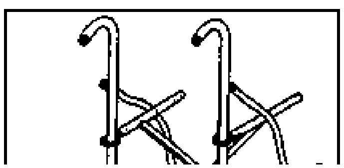
Folding is important. For many wheelchair riders, it is essential that their chair can fold, to fit into a narrow space. This is especially important for those who need to travel in a bus, carry their chair in the back of a car, or pack it on a donkey.

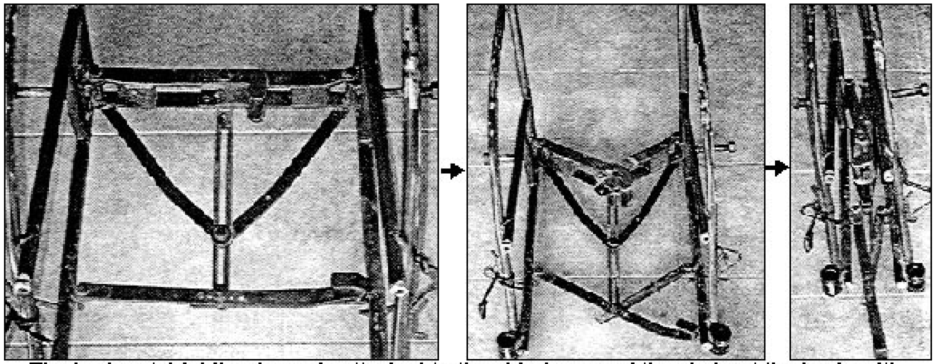


Problem: The original Whirlwind design included an upright X-brace that folded like scissors, as do most commercial chairs. But to fold well, the measurements, welds, and alignment must be exact. In PROJIMO, as in many small shops run by disabled persons, many workers are still learning their skills. There are few highly skilled crafts-persons. The resulting wheelchairs were often very difficult to fold. Users expressed their frustration.

Solution: **a horizontal folding device.** To solve this common problem, Ralf and friends experimented with alternative folding devices until they came up with one that was more fool-proof. The new design folds horizontally, rather than vertically. Although it has more pieces and uses more welds than the X-brace, it requires less skill and precision to build, and gives consistently good results. PROJIMO now uses this new folding device in all its Whirlwind chairs, and has had fewer complaints.

Chair in Half Open Position

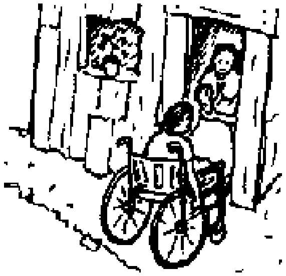
The X-brace folds like scissors.

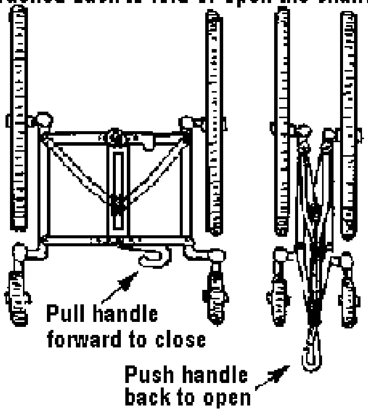


The horizontal folding brace is attached to the side frames of the chair: at the back, with short, strongly-welded vertical hinges, and at the front, with vertical bolts that allow the cross bars to pivot.

Narrowing the chair to get through doorways. On experimenting with the new folding mechanism, users discovered that they could easily narrow the width of the chair while sitting in it. They pull the handle under the seat forward, and then pull the wheels in, closer to their body. This offered a solution to another big problem of wheelchair riders in many countries: getting through narrow doorways. (See Luz's story on page 17.)

A short handle below the front of the cloth seat can be pulled forward or pushed back to fold or open the chair.





With the new design, to go through a narrow door the user simply pulls the sides of the chair in against her hips, and rolls through. (With an X-brace, narrowing the chair is much harder, because it folds against gravity and the person's own weight holds it wide open.)

Adjustable chair and seat width. The horizontal folding mechanism also lends itself to adjusting the seat width to match the hip-width of the user. Small holes can be drilled in the cross bars of the adjustment device, so that the chair width can be adjusted, depending on which set of holes the center bolt is passed through.

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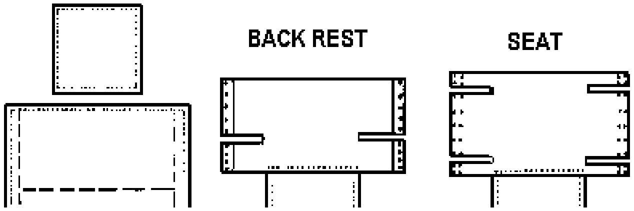
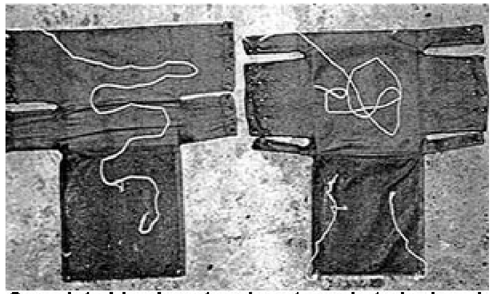
Upholstery. To avoid having to make new upholstery with different measurements for different seat adjustments, Ralf has devised wrap-around seat and back-rest cloths that can be laced up at different widths.



The patterns for the back-rest and seat are similar. They consists of one square just a little bigger than the desired size of the back-rest or seat, and another square, 4 times as big.

Hem the edges of both squares to prevent fraying. Then, fold the big square in half, and cut grooves as shown here. Sew together at all edges, except where the small square will be attached. Turn the resulting sack inside out, and sew on the small square. Make holes for lacing as shown.



Completed back-rest and seat, ready to be laced into place. The small square folds over and protects the lacing.

Jaime laces the back to the seat. The lacing can be loosened or tightened for different wheelchair widths.

How appropriate is the new folding mechanism and adjustable seat? The answer depends on who you ask. Wheelchair riders and users (including Ralf) have mixed feelings. One of the beauties of the early Whirlwind design (with the vertical X-frame) is its simplicity, streamlined look, relatively few parts, and few welded joints (all of which contributed to the chair's low weight and low cost).

The new folding mechanism with its adjustable seat width solves a number of problems but sacrifices some of the Whirlwind's graceful look and adds a bit of weight. Some users like being able to adjust the chair to their own body width, and to narrow it easily to pass through narrow doorways. Other users think it "looks funny" and prefer the more conventional X-brace. (For some people, appearance is more important than function.)

The PROJIMO wheelchair builders are delighted because - although the new folding mechanism takes more welds and looks more complex - for them, it is easier to build successfully. That is important. **Designs must be appropriate for builders as well as users.**

The search for better designs continues. Ralf's team is now experimenting with a folding mechanism developed by blacksmiths in Nyabondo, Kenya. This uses a vertical X-brace that is easier to build than is Ralf's original design.

There is always room for improvement.
And improvements are always possible when builders and users work together creatively.

This Chapter continues to the NEXT page

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Nothing About Us Without Us
Developing Innovative Technologies
For, By and With Disabled Persons
by David Werner

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CHAPTER 31

For Long Runs on Lousy Roads: A Hand-Pumped Tricycle

ALEJANDRO'S CHANGING MOBILITY NEEDS

ALEJANDRO *was 12 years old when he was shot through the spine by a policeman. The events surrounding this brutal incident will be briefly described in* *Chapter 40, page 261**, under the heading, "Defense of Human Rights." Here, we will focus on Alejandro's changing mobility needs, and the equipment designed at PROJIMO to help him move about at the different stages of his rehabilitation and re-entry into community life.*

Alejandro first arrived at PROJIMO two months after his injury. For a child who was completely paralyzed from the mid-back down, he was in good spirits. Although he had been told he might never walk again, he was eager to get back into action. He progressed through using 3 forms of locomotion: ***a gurney, a wheelchair, and a tricycle****.*

A GURNEY to Recover from Pressure Sores and Prevent Urinary Infections

Like so many spinal-cord injured young people who come to PROJIMO, Alejandro already had deep pressure sores when he arrived. The sores had begun to form while he was in the hospital. Therefore, his first mobility aid was a wheeled cot, or gurney (see Chapter 37). This allowed him to lie on his stomach, taking pressure off the sores on his butt. In the wheelchair shop, the gurney was built to the boy's size.

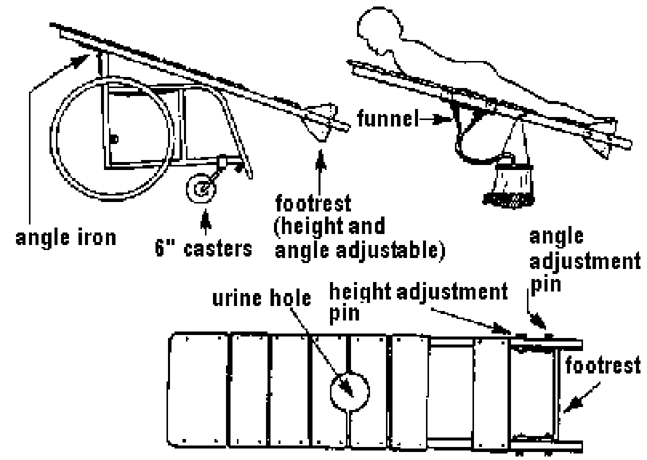
At Alejandro's request, **a simple rack to hold a container with drinking water** was made from a plastic gallon bottle and attached to the front of the gurney. Handy access to drinking water is essential, especially in a hot climate, because *one of the best ways to prevent bladder and kidney infection is to drink lots and lots of water*. For Alejandro to have his own water container (with its attached plastic straw) within easy reach wherever he went, was an important (and possibly life-saving) measure.

The gurney had another feature to help prevent urinary infections: **a built in free-flow urinal** (see next page).

With spinal-cord injury, the person usually loses bladder (and bowel) control. To get the urine out and prevent wetting the clothing, a catheter (thin tube) is often used. Whenever possible, however, it is important that spinal-cord injured persons avoid using a permanent (Foley) catheter (see box at right). If the catheter is left in continuously, it is likely to cause urinary infections (see page 147).

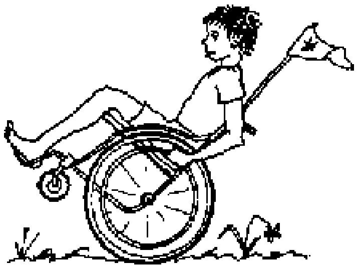
WARNING: For persons with a spinal-cord injury (or spina bifida), pressure sores and urinary infections are the most common causes of death,

To help Alejandro keep dry, and yet avoid the need for a permanent catheter, his gurney had a hole cut out of it in the position of his genitals. This way, he could urinate into a container hanging under the gurney, without needing a permanent catheter. (The hole also prevents injuring the genitals, which, because they lack feeling, can be easily injured.) Gurneys can be built with a potty or other removable container attached under the hole in the gurney. Or, a large funnel can be mounted under the hole, with a plastic tube that drains into a urine bag.



A Wheelchair to Take Part in Village Life

Partly because he was so active on his gurney, Alejandro's large pressure sores healed quickly. Within 2 months, he was ready for a wheelchair. He experimented with different models at PROJIMO until he had an idea of what would work best for him. The wheelchair builders then took his measurements and built a version of the **Whirlwind wheelchair** (see Chapter 30). In his new chair, Alejandro was extremely active, and he took part in a wide variety of adventures with other youth in the village, including swimming in the river.



At first, Alejandro used an air-filled cushion on his wheelchair to prevent pressure sores. But even with the cushion (and in spite of repeated advice from Mari and others to often lift his butt off the seat) Alejandro began to develop new sores.

When well-made, tests show cardboard cushions prevent pressure sores as well as costly air-balloon cushions do.

His younger brother, Neto, with guidance from the PROJIMO team, helped him make **a personalized cushion out of layers of cardboard** glued together with white glue (see Chapter 27). Before the glue was dry, they sprinkled the cardboard with water to make it softer. Then, Alejandro sat on the cushion so that it would take the shape of his backside. Finally, they cut an oval out of the back part of the cushion to further reduce pressure over the butt-bones where the pressure sores often form. To make the cushion softer, they covered it with a layer of fairly dense foam rubber. The whole thing slipped into a protective cloth pillowcase.

With his cardboard cushion - plus daily treatment of the sores with honey and sugar, and remembering to shift his weight regularly - Alejandro's sores healed rapidly.

Time passed ... When Alejandro first came to PROJIMO, the team had realized that the treatment of his pressure sores would take months. Because proper management of his sores at home was unlikely, they arranged for him to stay in Ajoya (where PROJIMO is based) and to attend the village school. For a time he did well, but eventually he dropped out and got married to a girl of his own age (14 years old). He took his young wife to his parents home, but life was difficult. His parents drank a lot and neither was employed. Often the family went hungry. Alejandro began to think of how he and his young wife could have a better future.

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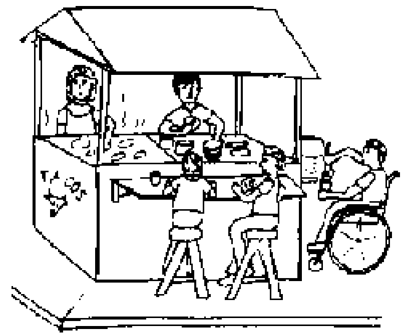
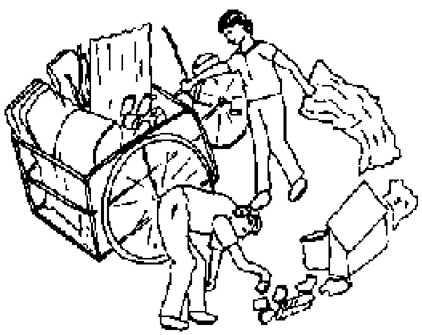
A TRICYCLE to Continue Schooling



Fortunately for Alejandro and his family, PROJIMO has relations with *Liliane Fonds*, a non-government charity in Holland that assists individual disabled children and their families. Liliane knows that a family's economic survival is basic to a disabled child's survival and well-being. A little "seed money" from Liliane helped the family begin to earn a living through the informal economy. Marcelo, at PROJIMO, built **a metal cart for frying and selling tacos**, which the family could put on a street corner in the evening and earn a modest income.



Later, Liliane financed a strong, **pedal-powered tricycle with a big carriage area**. With this, Alejandro's brothers (who could find no formal employment) rode through the city streets collecting old cardboard, aluminum cans, and scrap metal. They could sell these for enough to put a bit of food on the family table.

Even so, sometimes there was not enough to eat. In Mexico, as in so many countries, unemployment increases and wages decline as the gap between rich and poor continues to widen. Unable to do many forms of physical "unskilled" labor, Alejandro began to think about returning to school.

Dolores Mesina - a big-hearted social worker who had polio as a child and has close ties with PROJIMO (see page 261) - arranged for Alejandro (at age 16) to get a **scholarship to a technical school**. Alejandro could study practical skills there, ranging from small-motor repair to secretarial and computers skills. He was eager to attend.

However, there was a major difficulty: how to get there. The school was on the far side of the city, 5 kilometers away. Buses were not equipped to take wheelchairs, and they were terribly crowded. Taxis were too costly. The roads were too rough and the traffic too heavy for travel in his wheelchair to be safe.

Alejandro thought of a solution for getting to the distant school: **a hand-powered tricycle**. Geoff Thomsby, a wheelchair builder with experience in Africa, had volunteered at PROJIMO for over a year. He had taught the PROJIMO workers to build a hand-pumped tricycle that he had developed from models used in Cameroon, Africa. While at PROJIMO, Alejandro had tried out a tricycle, and loved it. With its large size and big front wheel, it zoomed safely over uneven terrain. For long distance travel, the rider could keep up a relatively high speed without tiring nearly as much as with a regular wheelchair, even a "Whirlwind."

Again Liliane Fonds assisted with the costs. Alejandro went back to PROJIMO and helped to repair a used tricycle, which the team agreed to let him have at a reduced price. The fact that Alejandro himself helped repair the tricycle gave him both the knowledge and the responsibility for its upkeep. Alejandro now cruises all over the city of Mazatlán, visiting friends and attending social gatherings. The tricycle has been Alejandro's ticket to a new level of freedom.

Village children help Alejandro reparr his hand powered tricycle.

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HAND-POWERED TRICYCLES

Strengths and Weaknesses

Although hand-powered tricycles are widely used in Asia and Africa, they are little-known in most of Latin America. But there is certainly a need for them.

Jaime teaches Alejandro to spoke the wheels of his tricycle.

Alejandro with his tricycle (when he was 16 year old).

The main advantages of the tricycle are that its large front wheel, large size, and hand-power mechanism (whether by crank or pump) permit **easier, faster safer travel over rough terrain**.

The tricycle is most useful for disabled people with specific needs, such as:

- Persons, like Alejandro, who **travel long distances** to school or work on rough roads or in heavy traffic.
- Persons with **only one hand** strong enough to push a wheelchair - such as those with one-sided paralysis.
- People who **can walk short distances**, with or without crutches, but need wheels for going longer distances.

Disadvantages. The tricycle is not ideal for every rider's needs. Its **large size** (length and width) makes it unfit for indoor use (or for bus travel).

Inez gives one of his daughters a ride on his tricycle wheelchair.

At PROJIMO the two workers who at once fell in love with the tricycle were Armando and Inez. Both use crutches. Although Armando walks with crutches in the wheelchair shop, he enjoys using the tricycle to move about in the village. It is easier for him than a wheelchair, because one arm (as well as both legs) is weak from polio. He powers the tricycle with his stronger arm, and steers it with his weaker one.

Inez's arms are both strong. But he lives at the far end of the village, a long distance away on crutches. The tricycle gets him there quickly. It is big and strong enough so he can give his two young daughters a ride on it, which they love.

A Tricycle and Dignity for Don Miguel

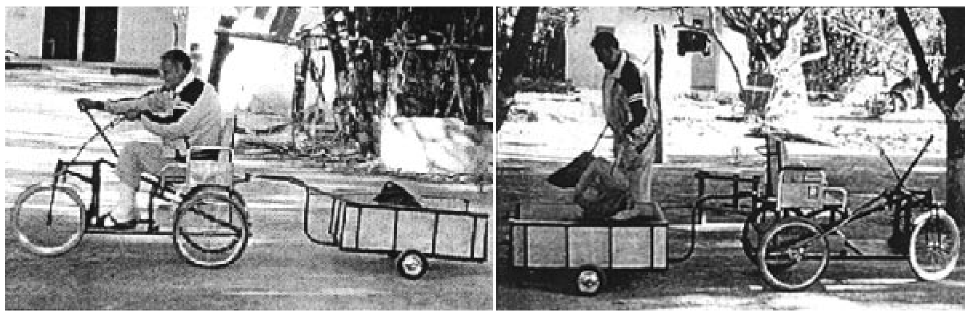
A person who found the tricycle wheelchair especially enabling was **DON MIGUEL**. Don Miguel (who recently died) was an elderly man who had come to PROJIMO with a huge, open sore (ulcer) on one leg. The lack of feeling and scars from burns on his hands and feet gave the clue that he had Hansen's disease (leprosy). At first he denied this. But, later, he admitted that he had undergone treatment for the disease.

The ulcer needed long-term treatment, and the leg needed to be kept elevated (higher than the level of his heart) when he was not physically active. So, Don Miguel was invited to spend an extended period of time at PROJIMO, for treatment and rehabilitation.

In truth, Don Miguel's biggest need was to feel respected and needed. Because of people's fear and lack of correct information about leprosy, he had been rejected wherever he went. His relatives occasionally helped him with a little money, but preferred that he keep his distance. He had a kindness and wry sense of humor about him, born of loneliness. A good man, but misunderstood.

In PROJIMO, Don Miguel found a new family: people who welcomed and accepted him. Why a group of disabled persons should be more accepting of someone with leprosy than most other people, is hard to say. Perhaps it was because they, too, have felt rejected, slighted - or worst of all, pitied - for their various disabilities. Stigma is stigma.

In PROJIMO, Don Miguel discovered not only that he was welcome, but needed! Though he had arthritic pain secondary to his disease, he was more able-bodied than many PROJIMO workers. He began helping in any way he could, He moved and bathed persons in need of assistance. And he took over the maintenance of the grounds and playground.



There was always a lot of garbage to clean up. This Don Miguel would do religiously every morning. But moving about was difficult for him. One day, he asked if he could use a tricycle. Everyone said yes. To help him with the clean-up, **the wheelchair builders made a large cart which could be attached to the back of the tricycle, like a trailer**. Don Miguel would ride around the grounds, getting out here and there to put trash into the cart.

Don Miguel stayed at PROJIMO for nearly two years ... the last two of his life. He was a good influence on the team, a peacemaker in times of strife. Everyone liked him. One day he said he was leaving, and a few weeks later the team learned from his family that he was dead. He had been a warm and stabilizing influence on the program.

We miss him.

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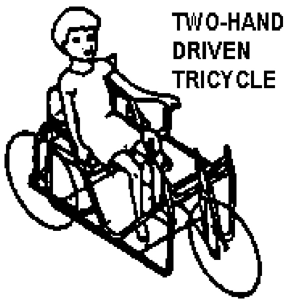
Design and Construction of A Lever-Powered PROJIMO Tricycle

The PROJIMO tricycle is one of many different designs in different parts of the world. One feature of the PROJIMO tricycle that differs from many is its **lever-powered drive**. Most tricycles are powered by hand-rotated pedals (often modified bicycle pedals), and the power is transferred to either the front wheel or one of the back wheels by means of a bicycle chain. The problem with chains is that they can break fairly easily. The lever-powered drive mechanism is more resilient and requires less maintenance. Also, rear-wheel (rather than front-wheel) drive provides better traction on sand and steep slopes.

The front steering mechanism uses a fork made with strong metal tubes. The front wheel is a 24-inch bicycle wheel.

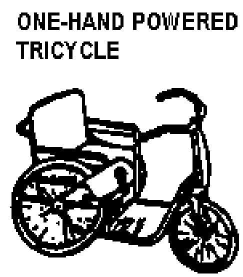
The hand-powered lever is attached to an arm welded to the hub and a bracket welded to the frame. It works like the drive mechanism of a railroad train.

Examples of Different Tricycle Designs from Different Lands



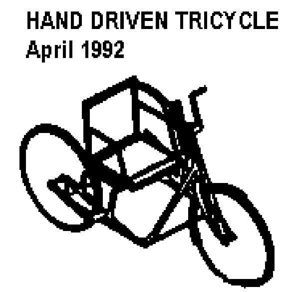
Personal Transport for Disabled People - Design and Manufacture

AHRTAG
Appropriate Health Resources and Technologies Action Group. Ltd.
85 Marylebone High Street
London, WIM 3DE
England



Asia-Pacific Disability Aids and Appliances Handbook, Part 1: Mobility Aids, 1982

ACROD / ICTA sub-commission
18 Argyle Street
Sydney, NSW 2000
Australia



ACTION ON DISABILITY AND DEVELOPMENT

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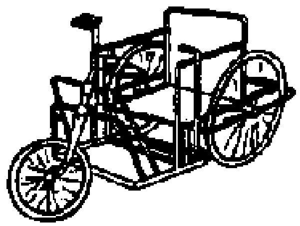
How to Make Basic Hospital Equipment

HANDICAP INTERNATIONAL



by Roger England and Will Eaves

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FRANCE
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Note: Some tricycles are powered with only one hand. Others are powered with both hands (in which case the steering mechanism and drive mechanism are usually on the same bar, attached to the front fork). Some have hand-powered drive pedals (handles) on both sides of the tricycle, so that when one of the rider's arms tires she can use the other. It is important to pick the design that best meets the needs of the particular user. Booklets exist on different designs of tricycle wheelchairs. Some examples are shown here. (Also see Resource List #2 at the end of this book, page 343.)

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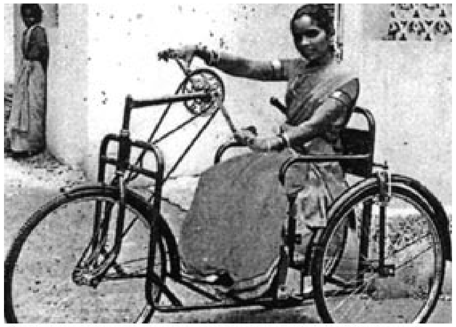
Worldwide Sharing of Tricycle Know-How, Coordinated by APPROPRIATE MOBILITY INTERNATIONAL

Great progress is under way in terms of the sharing of knowledge about different designs of hand-powered tricycles. A world-wide information sharing network has been launched by a group called *Appropriate Mobility International (AMI)*, based at Delft University of Technology, in Holland. Joep Verweij of AMI has collected information and photos on scores of tricycle designs from rich countries and poor, world-wide, He has assembled these in an Overview Report titled *Inventory of Tricycle Models* (see page 344). The wide diversity of design is a testimony to the creativity of disabled people and local craftspersons. Here are a few examples of this diversity, taken from the *Inventory of Tricycle Models*, and elsewhere:


Thailand. A hand-pump powers one rear wheel. Steers with foot. Heavy duty for hauling cargo.

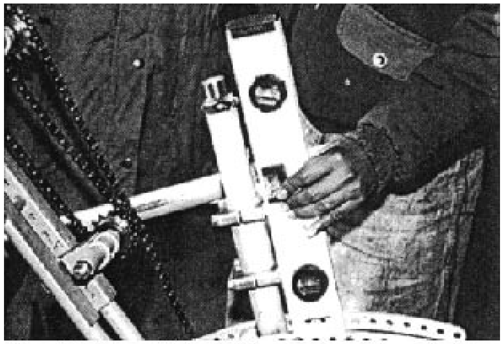

Vietnam. Designed in France. Steering column pumps back and forth to give dual rear-wheel drive.



India. Hand-crank powers the front wheel. Good for flat paved roads; poor traction on hills and sand.

Racing trike. Sold commercially in USA. Front-wheel drive. Rider's forward position increases traction.

Workshop managers from India and Sri Lanka discuss an experimental model for a new design of wheelchair, developed in partnership with Appropriate Mobility International (AMI), in Holland.



Most features of the AMI experimental model (shown on the left) are adjustable, so it can be tested by different riders with the wheels, hand-crank, and other parts at different angles and positions.

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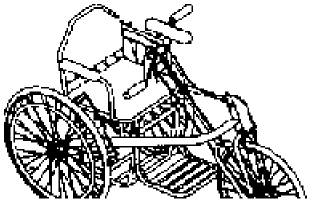
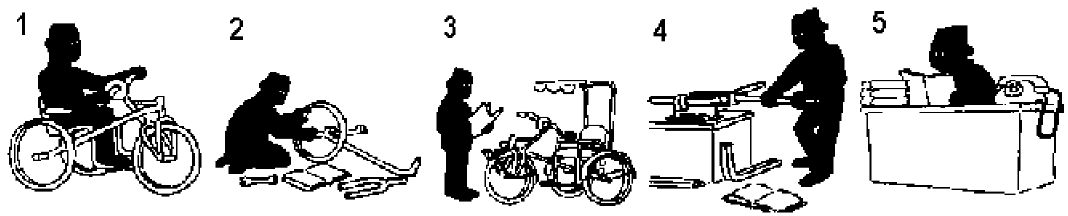
High-Tech Communications for Grass-Roots Shop Workers:
"Tricycle Production Manual," by the *Folks at Appropriate Mobility International*

Based on their research and the design perspectives of tricycle users and designers from all over the world, folks at AMI and the *Center for International Cooperation and Appropriate Technology* have put together a remarkable instruction manual. With **hundreds of line drawings and very few words**, the manual guides the reader through the steps of building an improved model of a hand-operated tricycle.

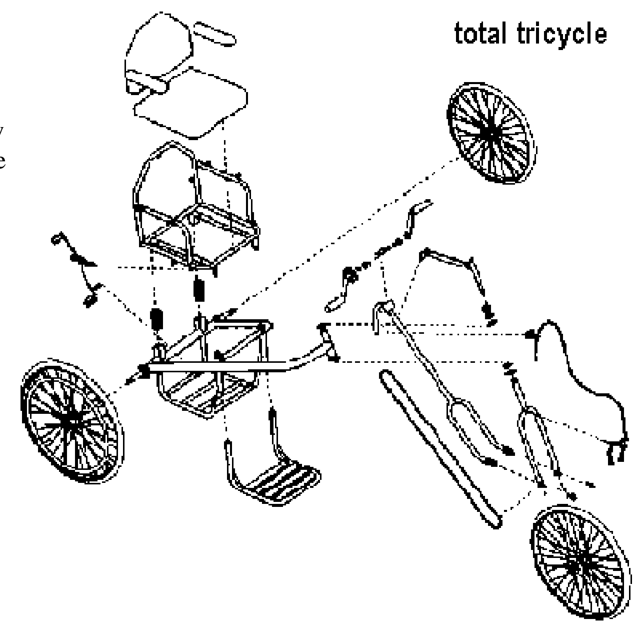
The Table of Contents of the Manual uses the pictures shown below to indicate headings:

1. TRICYCLE
2. PRODUCTION
3. ADDITIONS
4. MATERIALS
5. INFORMATION





Research in preparation of the manual included a study of people's ability to interpret pictures. As a result, many of the drawings - which have been done with great precision with a computerized graphics program - are 3-dimensional, as shown right.

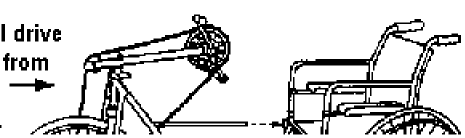


This innovative manual deserves careful study, not only by wheelchair builders, but by anyone interested in exploring new ways of communicating clearly. Through the use of step-by-step series' of computerized drawings, it attempts to bridge the gap between sophisticated technology and the traditional skills of local craftspersons, whose understanding tends to be based on real (or at least realistically drawn) objects rather than written words. (See Resource List #2, on page 344.)

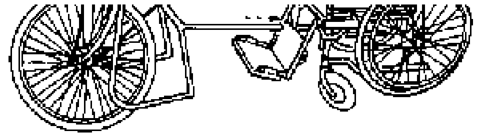
A CONVERTIBLE TRICYCLE-WHEELCHAIR FOR ALEJANDRO

At the time this book went to press, Alejandro had been offered a scholarship to study English at the *Academia de Inglés Golden Gate*, in his home city of Mazatlán. (The Academy is run by a disabled youth, José Angel Tirado, whom PROJIMO assisted in his childhood. See page 315.) To get to the Academy on the rough, heavily trafficked roads, Alejandro could use the sturdy tricycle made for him at PROJIMO. But this outdoor vehicle was much too big to move about inside the Academy or to enter a classroom.

Therefore the PROJIMO team decided they should make a tricycle that Alejandro could quickly convert into an ordinary wheelchair for indoor use. Armando remembered seeing a design for such a tricycle in a booklet called *Making Health Care Equipment* (see page 343). It consisted of a standard wheelchair to which a tricycle front-end (including a large front wheel, hand pedals, and a steering mechanism) could be easily attached or removed.



Alejandro thought that such a trike would meet his needs. For long distance rides on rough roads, he could use the full tricycle. On arrival at the Academy (or at home) he could unplug the front section and enter the building in the compact wheelchair.



Design from the booklet "Making Health Care Equipment" by Intermediate Technology International.

For this experimental model, Armando and Marcelo adapted a standard donated wheelchair. They used a 24-inch bicycle wheel at the front. They welded together a tube frame, with rods that could slip into the side tubes of the chair seat.

Front part of the tricycle removed from the wheelchair.

Marcelo experiments with the new design.

Need for improvements:

At the time of this writing, the experimental design had been built and tested, but still had problems. The chain that linked the hand crank to the front wheel occasionally jumped off the sprockets (which needed better alignment). Also, some sort of device or blocks were needed to hold the chair's caster wheels a couple of centimeters off the ground - so that Alejandro can plug in or remove the tricycle unit while sitting in the chair.

Tricycle designs must be adapted to local needs. In urban Mexico, a standard tricycle is too long to fit into buildings and classrooms. In rural Africa, a standard tricycle is too wide to ride on narrow dirt trails. An African boy's innovative solution is shown on the next page.

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PAFUPI BUILDS HIS OWN TRICYCLE FOR NARROW TRAILS

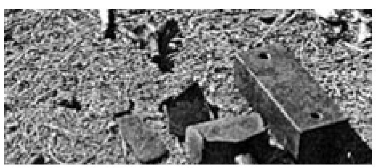
PAFUPI lived in a remote village in Malawi, Africa. Because his legs were paralyzed by polio, he had started school later than most children. The school was too far away to walk to on his braces and crutches. He dreamed of having a hand-powered tricycle. But the trails where he lived were much too narrow for the big, wide tricycles made in the cities.

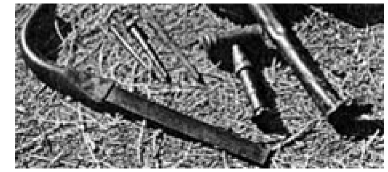
Pafupi was good with his hands and had an inventive streak. As a child he had made a guitar from old tin cans and scraps of leather. And he had learned to play it fairly well.

When he was 17, Pafupi decided to make a small tricycle that was narrow enough to ride on local trails. He used parts of 3 old bicycles, an old flywheel, and bits of scrap metal. He had no welding equipment. So he hammered the ends of the pieces together precisely, like interlocking fingers. Although the joints were slightly flexible, they were remarkably strong.

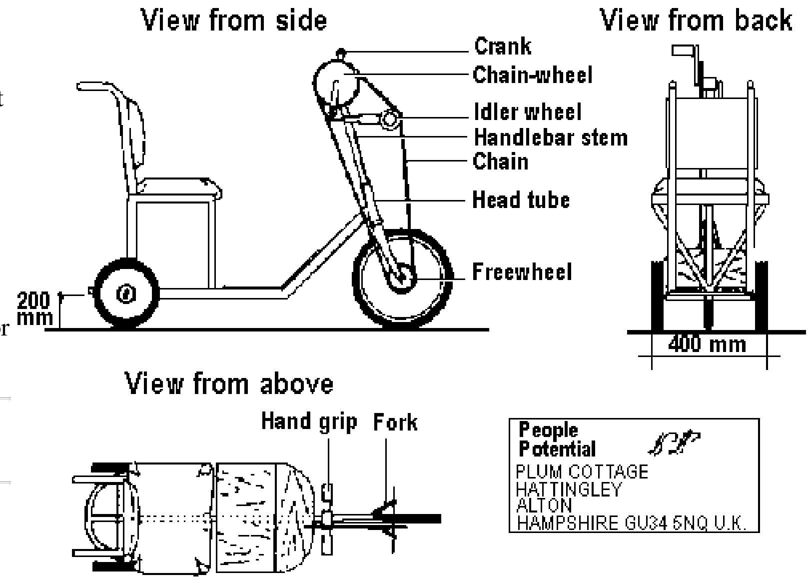
On his way home from school, Pafupi rides his improved "narrow gauge" tricycle, designed for the narrow trails. (See Left)

The tools Pafupi used to make his tricycle were very basic: a small block of iron which he used as an anvil, 2 hammers, and a piece of an old hack-saw blade held in a curved metal pipe. (See Right)





On a trip to Malawi, Kennett Westmacott, an innovator of disability aids, saw Pafupi on his home-made tricycle. (In England, Kennett and his wife, Jean, run *People Potential*, where they teach ordinary people to design and make simple assistive devices. See pages 72 and 74). Fascinated by the appropriateness of Pafupi's home-made tricycle, Kennett and his students tried to build one like it in a training workshop. But their modified version had problems. To get it to work well, the group had to rebuild the tricycle, closely following Pafupi's design. Then they modified it with a bigger front wheel and other helpful changes.



An outstanding feature of Pafupi's tricycle was that he could pedal it in reverse (make it back up), something Kennett had not seen before in small, chain-driven tricycles.

The group was amazed that Pafupi - a viliage boy in primary school - was able to create such a well-adapted and functional vehicle, all done with very simple tools and without welding. Their respect for the skill and creativity of disabled villagers increased greatly.

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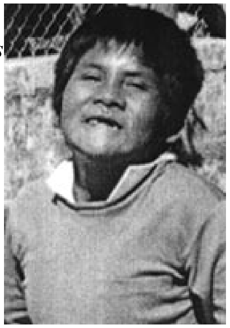
CHAPTER 32

Mobility Aids, a Walking Toilet, and a Seeing-Eye Person for Carlos



CARLOS *is the son of migrant farm workers from Oaxaca, one of the poorest states of Mexico. During harvesting season, his family used to come north to Sinaloa (the state where PROJIMO is located) to pick tomatoes. When he was 8 years old, Carlos already worked with his parents in the fields. Sadly when he was 10, the boy was hit by a truck and his brain was severely damaged. He remained mentally and physically disabled, and also visually impaired.*

Months after his accident, Carlos was taken to PROJIMO by state social workers. While he was still in the hospital, his parents had abandoned him. Apparently they had gone back to Oaxaca, without leaving an address. The social workers asked if PROJIMO could provide rehabilitation for the boy. In effect, PROJIMO became Carlos' new family.

On arrival, Carlos already had secondary physical and emotional problems. His spastic body had become very stiff, and he had contractures of his hips and knees. He was almost totally blind, and his mind did not function well. He had very little short-term memory and difficulty learning even simple things. The few words he spoke were mostly abusive swear words. He got angry easily, and often cursed and spit at persons trying to help him. He would repeatedly plead "I want water!" or "I want food!" even when he had just had plenty to eat and drink. He constantly wet and pooped his clothing and bed.

Carlitos (as he was affectionately called) needed a lot of personal assistance, plus a huge amount of understanding and patience. Fortunately, an older woman named Rosa, who has worked at PROJIMO for years, became like a mother to him. Rosa lovingly bathed him and washed his soiled clothes 2 or 3 times a day.

Mobility. To help Carlitos move himself about, one of the first things the shop-workers did was to build a wheelchair adapted to his size and needs. At first he could not move his wheelchair at all. But, little by little, he learned to roll it about. In time, he could more or less find his way on the pathways between buildings.

Water Play as Therapy. In preparation for standing and walking, the team helped Carlitos with range-of-motion and stretching exercises. These helped to correct contractures and reduce the spasticity of his hips and knees. At first, he angrily resisted the exercises. But when the team tried working - and playing - with him in water, he loved it. The water supported his weight and let him move without the fear of falling. His pleasure and activity in the water seemed to help his stiff body to loosen up.

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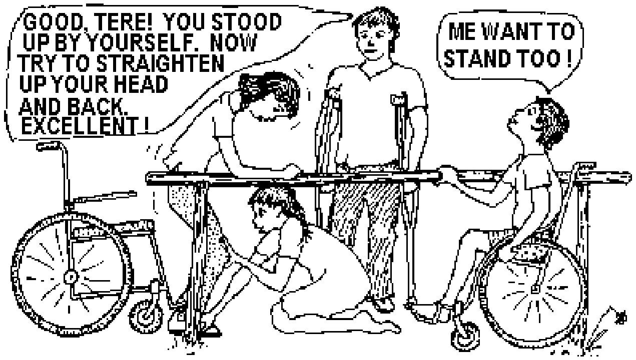
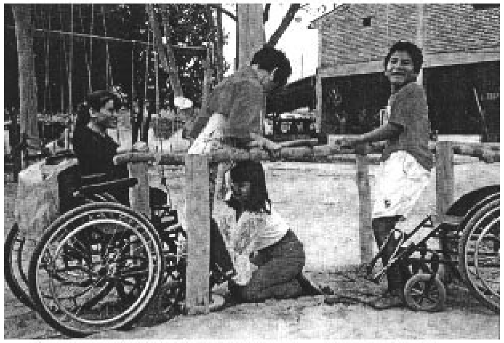
Standing. Although Carlitos' knees still bent stiffly when he tried to stand, the team felt he had the potential for learning how to stand and walk. At first he was non-cooperative, and understandably so. After nearly a year without weight-bearing, standing hurt his feet. But with daily practice his feet toughened.

The team found that the best way to get Carlos to try to stand was to put him with another child who was learning to stand.



Carlitos watched Tere trying to stand at the parallel bars. When Tere's helpers praised her enthusiastically for her efforts, Carlitos suddenly said, "Me want to stand!"



He made an effort to do so ... and finally succeeded in pulling himself up to stand.

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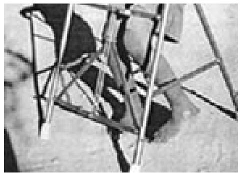
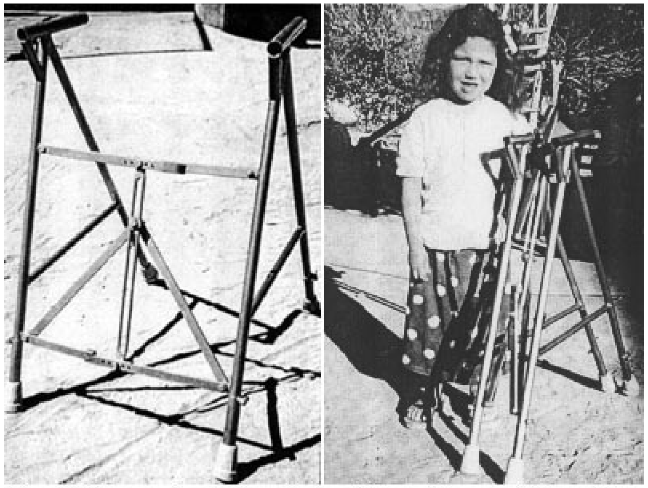
Walking. When Carlitos first tried to stand at the parallel bars he had very poor balance. He practiced daily. Little by little, his balance improved until he could take a few steps, holding onto the bars.

After months of practice, he learned to walk back and forth between the bars with fair stability. When Carlos began to say "I want walker!" the team asked Jaime to design a walker that would meet the boy's needs.

Mari and Inez tested him with walkers of different sizes and heights. At last they found a combination of features that allowed him to stand straighter and more firmly. Jaime, a paraplegic wheelchair builder who works lying on a gurney (wheeled cot), built the walker out of steel tubing. He used thin-wall electric conduit tubing, the same material used to make the wheelchairs.





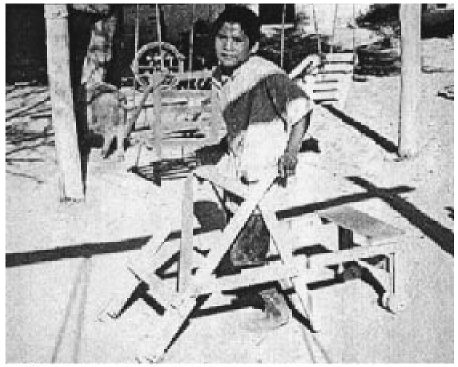
The folding mechanism worked well, providing a stable walker that was easy to fold.

A Wooden Walker with a Seat

Carlitos enjoyed walking with his new metal walker. But his attention span was brief and he tired quickly. After a few minutes, he would want to sit in his wheelchair. And a few minutes later, he would want to walk again. Because he was blind and had difficulty remembering, it was hard for him to find things. All day long he would call out to people to bring him his walker or his wheelchair. When everyone was busy there was sometimes a delay, and he would get angry and frustrated. "Carlos want walk NOW!" he would wail.

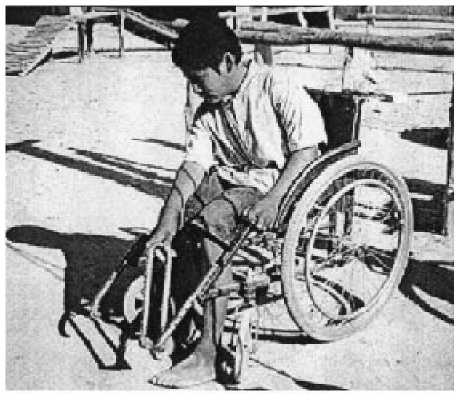
One day, Juán, a disabled carpenter and brace-maker, asked Carlos, "Carlitos, would you like a walker with a seat on it, so that you can sit down and rest when you're tired of walking?"

"Yes" said Carlos eagerly. "Carlos want walker with seat." So Juán made him a unique wooden walker with a seat.



Carlos walks with his wooden walker.

Carlos sits and rests in his walker.



To move from wheelchair to walker, Carlos first lifts aside the footrest. (A single footrest for both feet, hinged on one side, makes this easier for him.)

Then he stands and turns his body to sit on the seat of the walker. Next, he will lift his feet over the wooden bar.

Although transferring from his wheelchair to the wooden walker required stepping over the wooden bar that supported the seat, Carlos soon learned to transfer without help.

With his new walker, Carlos became more independent. He no longer needed to always ask people for help, and he began to take pride in doing things for himself. His self-help skills in walking helped prepare him for a better response to toilet training (see p.212).

A "Seeing-Eye Person" for Carlos. With his walkers, Carlos' walking improved. But being blind, he had a hard time finding his way. Someone suggested a seeing-eye dog. But it was easier to provide a "seeing-eye person."

At PROJIMO there are always young wheelchair users who have trouble moving about by themselves. These include Tere and Lupita, who have spastic arms and legs. One day, Tere was practicing standing at the parallel bars. At the same time, Carlos was walking in circles around the outside of the bars, holding on with only one hand. To do this, Carlos had to circle around Tere's wheelchair. Once when he took hold of the handles of her wheelchair, he laughed and tried to push it, like a walker. That gave Rosa an idea.

A Wheelchair as a Walker. When Tere finished her standing session at the bars, she said she wanted to go to the laundry area to wash her

clothes. Because she has difficulty moving her wheelchair on the uneven ground, she asked Rosa to push her. Half-joking, she said, "Carlitos, why don't you push Tere to the laundry area?"

Carlos grinned with excitement. "Yes! Carlitos want push Teresita!"

At first Tere was reluctant. Although she and Carlos were friends, she feared he would wheel her into a pit or tree. But Rosa explained to Tere that, by letting Carlos push her, she would be helping him with his therapy, his independence, and his self-esteem. So Tere agreed to give it a try.

Rosa guided Carlos' hands to the handles of Tere's wheelchair. Carlos pushed it eagerly. To keep on course, Tere told the blind boy where to go. At first he was confused. But after a while he learned to tell "Left!" from "Right!" and steer accordingly. Carlos had never seemed so happy, nor Tere more scared.

Carlos as a wheelchair-rider's attendant.

By that afternoon, Carlitos proudly also began to help Lupita move from one area of the playground to the other. He was walking more and better than he had ever walked before. And he was able to find his way, thanks to his "seeing eye persons." This mutual self-help by persons with different disabilities helped to build self-confidence in all who were involved, Carlos took great pride in his new role as a "wheelchair attendant."

Peer therapy. Tere, likewise, took pleasure in knowing that she was helping Carlos both develop his walking skills and gain a sense of being useful and appreciated. Lupita, whose mental handicap is as great as that of Carlos, was all smiles with the enthusiastic services of her newly found driver. In this way, multiply disabled young people have learned to help one another.

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Toilet Training as Preparation for Standing, Balance, and Manual Skills

Carlos' toilet training advanced slowly, with modest gains. At first, he always pooped in his cot at night. Then he began occasionally to crawl off his cot and poop on the floor. To reinforce this response and take it further, Juán - with the help of two village school children - made a simple wooden toilet seat that could be placed over a bucket next to Carlos' cot.

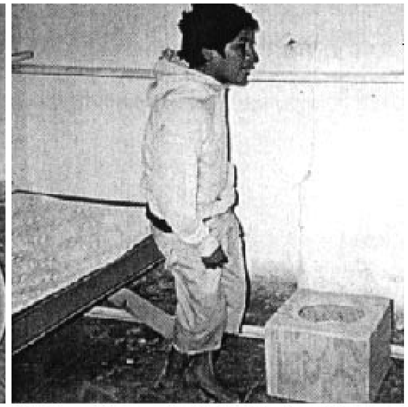
To involve Carlos more with **making his toilet**, the group asked him if he wanted to help sand the wooden seat. Carlos, always eager to "work," responded, "Yes, Carlos want sand toilet." Perhaps because he had already tried sitting on the toilet and identified it as *his*, he did the sanding with more energy and persistence than usual.

The next step was practice **using his toilet**. This involved sitting on the edge of the bed, standing up (while holding a metal bed frame turned on its side at the head of the bed), unbuttoning and loosening his pants, lowering his pants enough to avoid soiling them (while leaning against the bed frame), and sitting on the toilet. After using the toilet, he learned to repeat the same steps in reverse.

Carlos energetically sands his own toilet seat.

Steps in Carlos' toileting practice:


1. Moving from wheelchair to cot.


2. Standing up holding the bed frame.


3. Loosening his pants.


4. Shifting to the toilet.


5. Sitting on the toilet.

Carlitos still has a long way to go until he has no accidents in his bed. But his bedside potty not only helps him with toilet training, it also helps with standing, balance, dressing and undressing skills, body coordination, and manual dexterity. He is eager to learn new skills, and takes pride in having helped make the toilet he is learning to use.

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A WALKING TOILET FOR CARLOS


Martin, a village youth with severe chronic asthma, puts bigger wheels on Carlos' toilet walker so that it will roll more easily on rough ground.

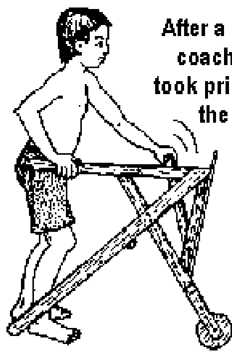
Problem. Carlos' new *walker-with-a-seat* (described on page 210) allowed him to sit down when and where he wanted. But the design had one big problem. Because the seat was mounted behind the space where he stood to push the walker, the whole device was over a meter long. This made moving in close quarters very cumbersome. If Carlos was to learn to walk to the dining room, he needed a walker that was more compact.

It will roll more easily on rough ground.

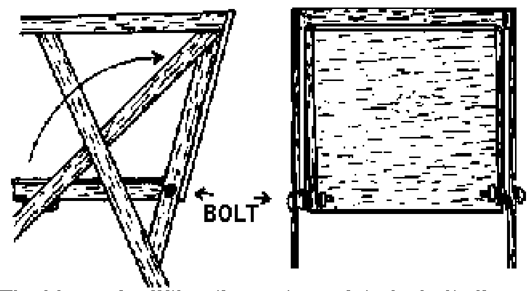
To solve this problem, PROJIMO designed a compact walker with the seat in front of him, not behind. Although he had to turn around to sit down, this walker had the advantage that it had *no poles to step over*.

Also, it *simplified transfers from the wheelchair*. Carlos could wheel his wheelchair between the rear legs of the walker, take hold of the walker's handle-bars and easily stand up.

Adaptation for urinating. One complication to having the seat of his walker in front of him was hygiene. Now that Carlos was partly toilet-trained, to urinate he would simply stand up and lower his pants. With his old walker (with the seat behind) that was all right. But to avoid wetting the forward-positioned seat of the new walker, the seat needed to be hinged so that Carlos could lift it out of the way before urinating.



After a few days of coaching, Carlos took pride in lifting the seat before urinating.

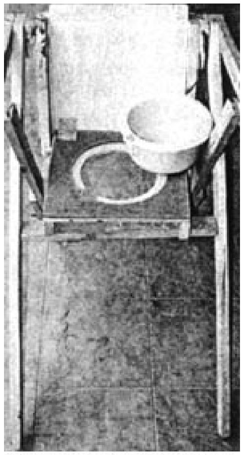


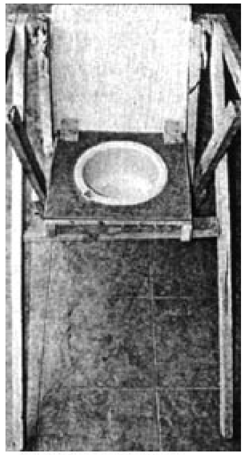
The hinges for lifting the seat consist of a bolt slipped through holes in the walker frame and the seat frame.

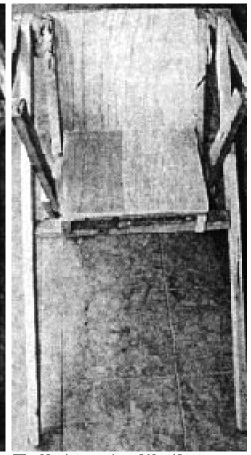
Adding a potty. The idea to adapt the walker as a portable toilet came from necessity. It was springtime. The plum trees at PROJIMO hung heavy with fruit. The ripest plums fell to the ground. Carlos would park his walker in the shade of the trees, sit on the seat, and lean over to feel with his hands for the fallen fruit. In a short time, he would stuff his belly to bursting.

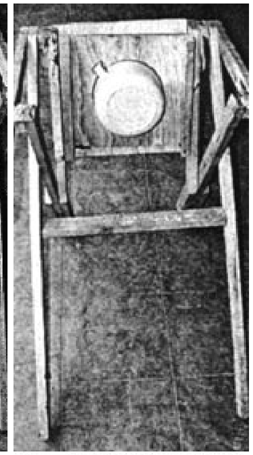
But this feast had a nasty side effect: *diarrhea.* Because Carlitos was blind and forgetful, he had not learned to take himself to the outhouse. Sometimes, when he had to go in a hurry, he called someone to take him. And sometimes he would poop in his pants. Rosa, who had to bath him and wash his clothes, was at her wits end.

To solve this problem, Polo helped to convert Carlos' walker into **a mobile toilet.** He cut a hole in the seat to hold a plastic bowl. Supported by its rim, the bowl could be lifted out to empty it. To use as an ordinary seat, a square board, hinged at the back, could be lowered over the bowl. To urinate, Carlos could swing the whole toilet up out of the way.


The new "toilet walker" with the potty removed from the toilet seat.


Toilet seat of the walker with the lid lifted out of the way.


Toilet seat with the cover closed over it to form an ordinary seat.

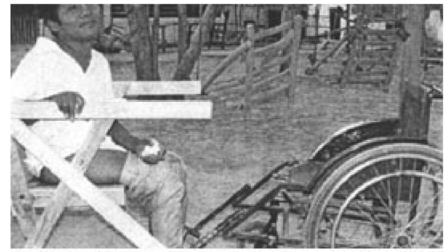

Walker with the entire seat, toilet, and cover tilted out of the way.

The invention saved the day. From one day to the next, Carlos became more independent in his toileting. The stimulation caused by his high-plum diet gave him plenty of practice, and he quickly learned to lift the lid and lower his pants.

What he never learned to do was to empty his potty. We all learned - the hard way - about the need to empty Carlos' potty often enough, especially during plum season.

One day, when he had filled his potty to the brim, he lost his bearings and fell over with his walker. He and the walker were covered with the potty's rank contents. Cecilia and the author helped with the clean up. It was no fun!

But, despite the occasional mishaps, Carlos loved his new walker. It not only gave him new freedom to move about, but helped him become more fully self-sufficient with his toilet.


Carlos proudly uses his new mobile toilet.

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Improvement

Bit by bit, in the 3 years that Carlos has been at PROJIMO, both his physical and mental abilities have improved. He has remembered songs from early childhood, and has learned new ones. He now talks more cleverly, remembers people's names, gets angry less often, and laughs gladly in response to friendliness or assistance. His common phrases now include "I want to walk" and "I want to work." He takes pride in using his toilet, and in staying dry and clean (sometimes).

His attention span is still brief, but for several moments at a time, he helps with activities in the toy shop. All in all - through a team effort in which disabled persons help each other - Carlos has come a long way.

Most important of all, Carlos has made friends and learned how to enjoy life and people.

In addition to better balance, he now has more self-confidence in his abilities. **It was a day for celebration when, at last, Carlos began to stand without any support or assistance.**

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CHAPTER 33

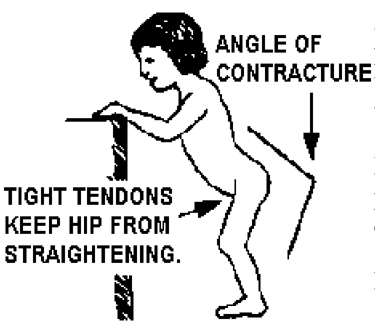
Bars for Beno, and a Walker that Turns into Crutches for Lino

This chapter looks at walking aids, harmful and helpful, for two children with spina bifida: Beno and Lino.

A Costly Walker for Beno that Did More Harm Than Good

BENO was four-years-old when he proudly showed the PROJIMO team how well he could walk with his big new chrome-plated walker. A month before his family (from a fishing village near the coastal city of Mazatlán) had taken him to a rehabilitation hospital where a doctor had prescribed the giant walker. It had cost the family a third of its year's earnings. But was it good for Beno?

Mari and Conchita had their doubts. The big square walker had a sling seat. To push it, the boy sat leaning forward with his hips bent almost at a right angle to his back. This was not a desirable position for a child with *spina bifida*, like Beno.



A child with spina bifida (page 131) often has weak muscles in the lower back and hips. This weakness is likely to lead to hip contractures that prevent the hips from straightening. As a result, many of these children have trouble standing up straight (or even lying down straight). Their butt tends to stick out backwards. If they will ever be able to walk upright and independently, they need exercises, activities, and assistive equipment that help stretch and straighten the hips.

Beno's big metal walker did just the opposite. Taking steps while seated in it, he was crouched in a position that would add to hip contractures, not prevent them! Also, walking in a sitting position prevented Beno from bearing weight on his legs, which is important for bone growth and muscle development.

Mari and Conchita explained all this to Beno's parents, and advised them not to let Beno continue using the walker.

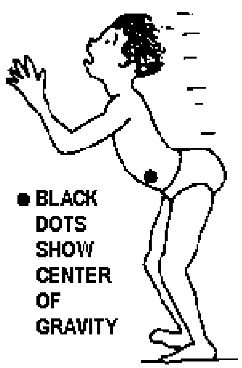
Parallel bars. As an alternative, Conchita adjusted the parallel bars in the playground high enough so that when Beno walked between them, they helped him to stretch his hips and to stand as straight up as possible. The parallel bars, which were made out of poles from the forest, had the advantage that the family could build their own at home at almost no cost.

Later, PROJIMO workers designed a wooden walker for Beno to help him stand as upright as possible and stretch his hip-flexor muscles. (An unusual walker for another child with spina bifida is illustrated on the next page.)

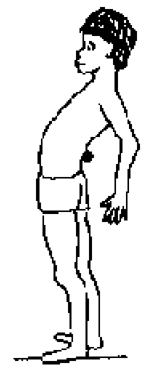
A Low-Cost Crutch-Walker for Lino

LINO, like Beno, was born with spina bifida. The defect in his spinal cord was sufficiently low on his back (near his butt) that he had fair upper leg strength. This meant he had a good chance of learning to walk, first perhaps with a standing board (parapodium) and then with a walker and perhaps crutches.

If a child with spina bifida is to be able to walk with crutches, or possibly without them, it is important that, from early childhood, every effort be made to prevent hip-flexion contractures. Care should be taken to keep the hip joints extended as straight as possible by means of exercises, positioning, and appropriate assistive devices.



With hip contractures the child finds it hard to stand.

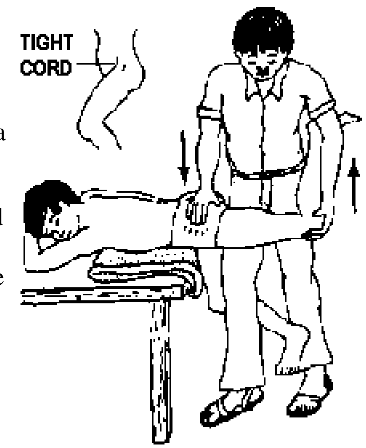


Thrusting his hips forward, this child can stand alone.

Because of weak lower back and hip muscles, the child with spina bifida is likely to find it hard to stand independently.

Some of these children learn to stand by thrusting their hips forward and their upper body backwards, so that their center of gravity is behind the hips. But to stand this way, it is essential that hip-flexion contractures be prevented (or corrected). In fact, **it helps if the hip joints over-extend,** or bend farther back than a simply straight position.

Lino was fortunate because, since early childhood, his family helped with exercises and positioning to keep his hips fully flexible. When he was three, PROJIMO helped him start to use a walker, with confidence that he would soon "graduate" to walking with crutches.



Hip-stretching exercise to correct or prevent hip-flexion contractures.

In designing a walker for Lino, Marcelo - an innovative shop-worker at PROJIMO - recalled his own childhood as a boy with both legs paralyzed by polio. Many disabled children who are learning to walk first use a walker and then, when they become a little more stable, change to crutches. For many children, the transition from walker to crutches is a fearful and traumatic experience. The walker gives them substantial stability. Crutches, at first, tend to wobble all over. In learning to use them, the terrified child often loses his balance and takes some nasty falls.

For this reason, Marcelo designed for Lino a **walker that could gradually be converted into crutches, with no sudden and frightening transition.** The walker consisted of 2 forearm crutches, which were connected with cross struts held in place with bolts and butterfly nuts. This way, the bolts could be gradually loosened to make the walker more wobbly and less stable. Then one after another of the cross-pieces and back-supports could be removed, until only the crutches were left.

This kind of innovation, which takes into consideration the child's worries and fears, is much more likely to take place when the technicians themselves are disabled.

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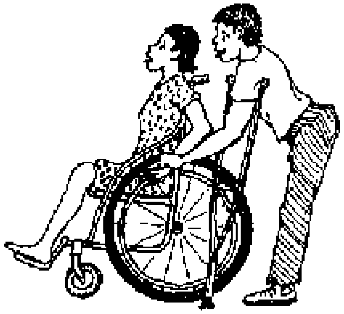
CHAPTER 34

A Front-Wheel-Drive Wheelchair for Aidé:

Lessons Learned from an Experiment that Failed

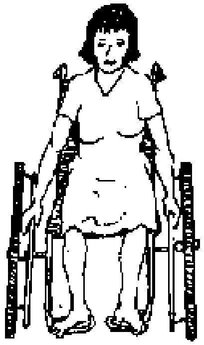
***AIDÉ** is a 14 year old girl who is multiply disabled as a result of brain damage at birth. Her mind works at about the level of a 6- or 8-month-old child. She cannot speak, but she does communicate, in a limited way, through grunts and facial expressions. Physically, she has good head and trunk control. But she has a lot of spasticity, especially in the lower part of her body. On her first visit to PROJIMO, she was unable to move herself about or feed herself. She had little sense of the potential usefulness of her hands. But she would occasionally take hold of different objects and hold them for a moment, then drop them.*

Aidé's family is very poor. Her parents put most of their energy into obtaining food and other resources to meet the family's basic needs. They did not know what to do with Aidé. As a result, they did little more than feed, bathe and clothe her.

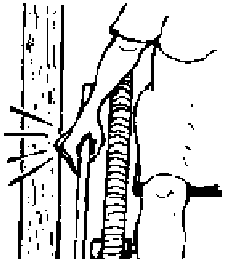


Unmet Potential. Even at PROJIMO, no one expects that Aidé will ever be able to do much for herself. She responded little to early stimulation activities or play-things that were tried with her.

The team thought that if Aidé could begin to move herself about a bit in a wheelchair, this self-created movement might increase her awareness of her body's position and the usefulness of her arms and hands. They provided a wheelchair. Inez held her hands on the hand-rims and rolled the chair back and forth, hoping she would begin to make the connection between the movement of her hands and that of the chair.



A New Wheelchair Design. Aidé tried PROJIMO's wheelchair for a little while, and soon gave up. One difficulty was that, with her spastic arms and shoulders, **she had trouble reaching the wheel rims**. PROJIMO-made wheelchairs, like most commercial chairs, have the large wheels at the back and the small caster wheels up front. A visiting therapist, Ann Hallum, pointed out that many persons with spasticity or limited range of motion find it hard to reach back far enough to effectively push the rear wheels. So PROJIMO's wheelchair makers, Armando and Jaime, decided to design **a wheelchair with the large wheels in the front and the small casters at the back**.



Another reason why persons like Aidé have trouble moving their wheelchairs is that the hand-rims, which are mounted on the outside of the large wheels, are so widely separated. So, Armando decided to try **mounting the hand-rims on the inner side of the wheels**. Closer to the rider's body, they would hopefully be easier for her to reach and to push.

A possible advantage of the inward position of the hand-rims is that the wheels are further apart. This wide wheel-base should provide stability and less likelihood of tipping over. The chair could be safer for persons with strong uncontrolled movements.

Also, for a person with limited control, hand-rims on the inner side of the wheels protect the knuckles from banging into doorways and other objects.

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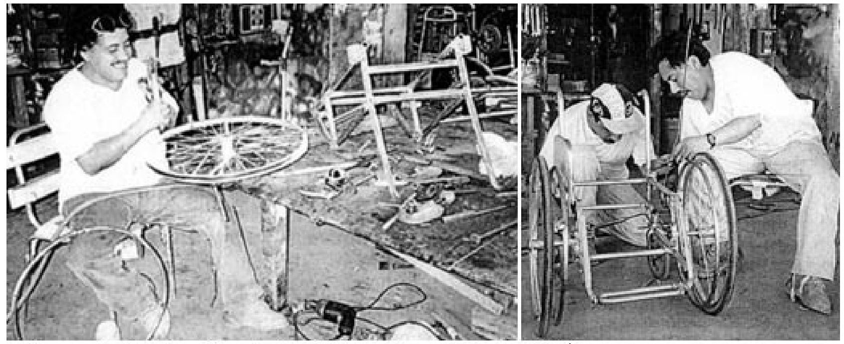
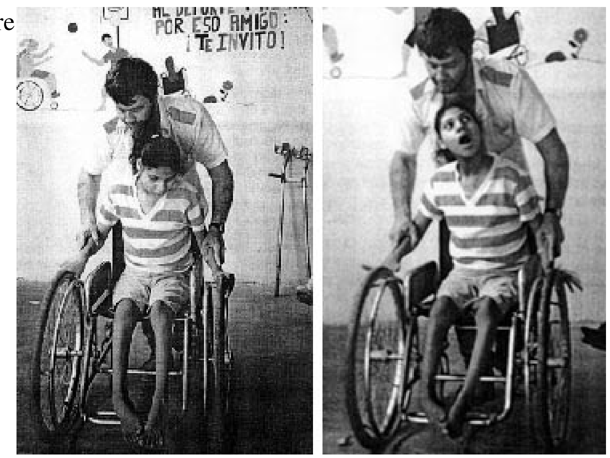
The newly designed chair, with front-wheel-drive and internal hand-rims, was built in 4 days. It was tested, not only by Aidé, but also by Tere, Lupita, and Carlos, all of whom have spasticity that makes it hard for them to push rear-wheel-drive wheelchairs.

Although the new chair did help to resolve some of the difficulties that some users had, **none were happy with it.**



Armando builds a front-wheel-drive wheelchair for Aidé.



Inez worked a lot with Aidé in her new chair. He found it easier to position her spastic hands on the wheels, now that they were mounted further forward. She seemed more comfortable that way and, in time, began to close her hands on the wheels.

Inez would hold her wrists and push them forward, helping Aidé to move the chair.

However, Aidé was unable to grip the hand-rims, that were mounted to the inside of the wheels. Her spastic fingers would bump into the wheels.

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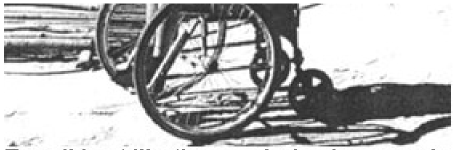
SHORTCOMINGS OF THE NEW DESIGN

It is still too early to know if the new wheelchair will benefit Aidé. So far, she still has not made much effort to push it by herself. However, she has begun to occasionally take hold of the large front wheels. This she had not done when the wheels were mounted further back.

Inez continues to work with Aidé daily. He hopes that, at some point, she will discover the joy of moving herself by pushing on the wheels.



Tere did not like the new design because she could not grip the inwardly mounted hand rims. Also, the poor traction of the large front wheels caused her to get stuck on soft loose soil.

Tere, Lupita, and Carlos also tried the front-wheel-drive wheelchair. Both Tere and Lupita could reach the front-mounted wheels more easily. But, when they tried to grip the inward-mounted hand-rims, like Aidé, they had trouble fitting their spastic fingers between the rims and wheels. So Armando widened the space between wheels and the rims.

But still the girls had trouble. The team decided that **putting the hand rims on the inner side of the wheels was simply not practical**. Neither girl found the new design acceptable.

Carlos, on the other hand, did not care where the hand-rims were. He always grips the tire, not the rim. However, the chair's unusually wide wheel-base gave the blind boy more stability when he tilted off a curb with one wheel, and in other spots where he might have tipped over in a narrow chair. **For Carlos, the wider wheel-base was helpful.** (To avoid accidents, Carlos also learned to "see" with his foot. See next page.)

Poor traction was the biggest problem with the front-mounted large wheels. On a smooth, level cement surface, Carlos, Lupita, and Tere could move the chair about fairly easily. But, on an upward slope, or on sandy or uneven ground, the front wheels slipped. This happens because the rider's weight is mostly over the small, back caster-wheels, which dig into sand and stop short on a pitted surface. There is simply not enough weight over the large front wheels for them to firmly grip the ground.

With the front-wheel-drive chair, the only way to get good traction on a sloping or irregular surface is for the rider to lean far forward, shifting her weight over the front wheels. This, of course, can be difficult, especially for persons with spasticity. The team concluded that **front-wheel-drive wheelchairs are of limited usefulness, particularly in rough, sandy, or uneven terrain.**

Learning from our mistakes. Not all innovations are successful. But we can learn a lot, even from efforts that fail. One lesson is extremely important:

Adequate trials of new designs are essential, and must include the intended users, within the local environment where they live.

Carlos and his "Seeing-Eye Foot"

Because Carlos is almost completely blind, he sometimes has a hard time finding his way in his wheelchair. However, he has figured out different ways to stay on paths and to avoid bumping into things.

Feeling his way with his foot, Carlos rolls his wheelchair off the cement path onto the soil. But sometimes he misjudges and tips over.

In Chapter 32 we saw how Carlos recruited a "seeing-eye person" to guide him while he pushes her wheelchair.

Since Carlos needs both his hands to drive his wheelchair, he cannot use a cane to feel his way, as many blind persons do. **Instead of a cane, he has learned to use his right foot.** He takes his foot off the foot-rest and puts it lightly on the ground in front of him. As he rolls forward, with his foot he can feel when he begins to go off a pathway or curb.

That way, he can often correct his direction before he has a mishap.

The wide wheel-base of the front-wheel drive wheelchair gives

Although Carlos' seeing-eye foot serves him well, sometimes he forgets to use it. Or, at times, he tries to maneuver his wheelchair over curbs or rough terrain, and the chair tips over. He has had a few nasty falls.

wheelchair gives Carlos extra stability. Here, he avoids falling off the curb by feeling his way with his foot.

For this reason, **the front-wheel-drive wheelchair, with its widely separated front wheels, is safer for Carlos than is a narrow chair**. The wide chair tips over sideways less easily. **Having the large wheels in front also appears to give more stability**.

Nevertheless, on loose or sandy soil, the front-wheel-drive chair has poor traction. Often, Carlos found himself trapped in pockets of loose soil where the front wheels would slip, and where he could not wheel himself out without help. As a result, **Carlos prefers his narrower, rear-wheel-drive wheelchair - even though he tips over more often**.

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WARNING:
Don't Assume That All the Designs You See in Pamphlets or Books on "Appropriate Technology" Are Appropriate.

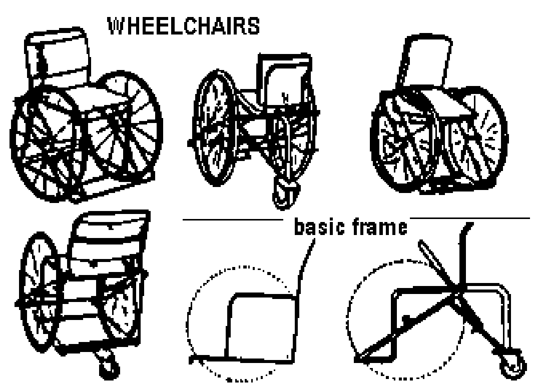
Many booklets on "appropriate technology" for disabled people show designs of wheelchairs and hand-powered tricycles with front-wheel-drive. Such chairs are often given to disabled persons, especially in Asia and Africa. They may work fairly well in exhibition halls, and on level hard-surfaced roads. But **on rough terrain they are likely to further handicap the user**. The rider may need an assistant to push her in circumstances where a better designed wheelchair or tricycle could provide more independent mobility.

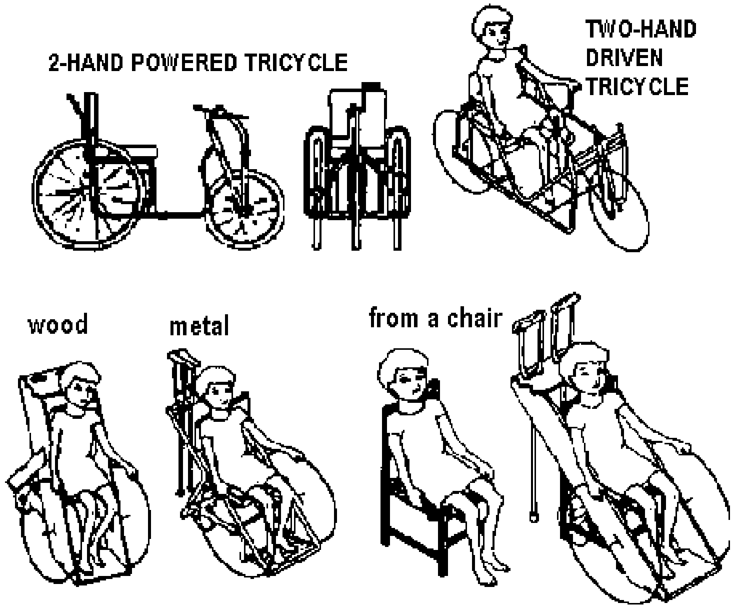
CAUTION:

The various designs of front-wheel-drive wheelchairs and tricycles shown here are taken from manuals and instruction sheets on equipment for disabled people.

But in some circumstances, **instead of increasing the rider's freedom through mobility, these models may cause greater dependence, need for assistance, or inability to venture forth.**

However ...
for certain children, a front wheel drive wheelchair may be the best choice (see below).



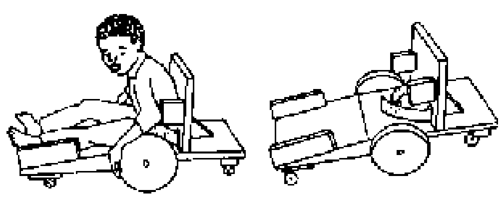


SOME CHILDREN WITH CEREBRAL PALSY FIND BIG FRONT WHEELS EASIER TO REACH AND PUSH

As with most rules, there are exceptions. Front-wheel-drive chairs are often inappropriate. But some children with spasticity, like Aidé, may find large front wheels easier to handle. Trollies and wheeled cots (see page 235) often work better with the big wheels up front.

This girl with spastic cerebral palsy finds front-wheel-drive easier.

A scooter board for certain children with cerebral palsy has been designed with the **large wheels positioned right under the child**, and with **small wheels both at the back and front**. For travel on rough ground, the child can learn to balance on the center wheels and barely touch the ground with the others.



This scooter slopes forward, so that a child with hips that thrust him backward, or that do not bend to 90 degrees, can sit up straight. (See positive seating, Chapter 4.)

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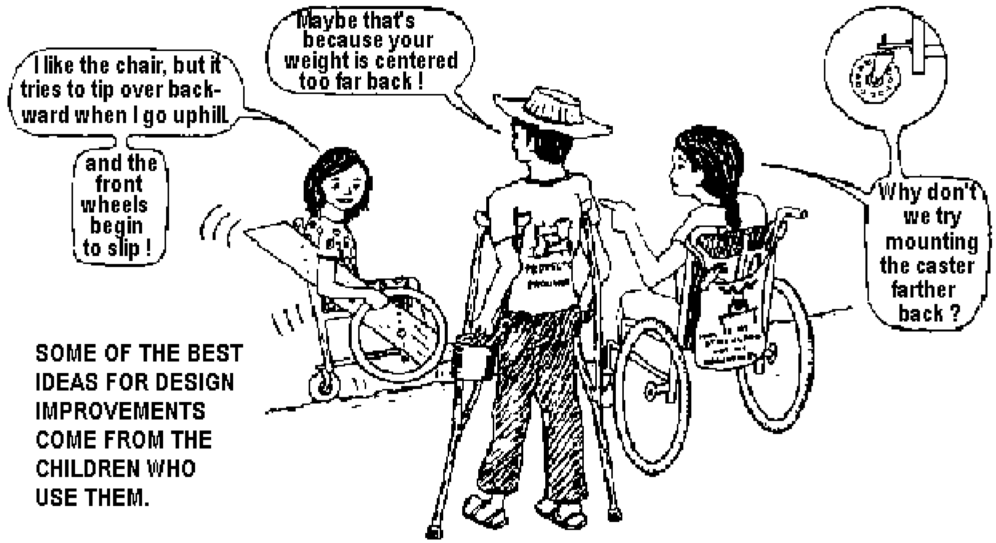
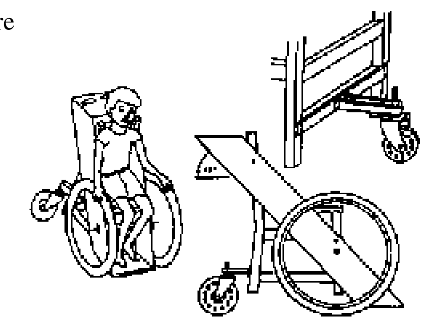
***REMEMBER:* Some of the best design improvements come from the ideas and suggestions of the persons who try them out and will use them.** This is true even for children. The child may not always be right. But doctors, therapists, and technicians are not always right either, especially if they do not live in the same situation and experience the same barriers and desires. By respecting each other's special knowledge and looking for solutions together, we can more nearly meet the disabled person's needs.



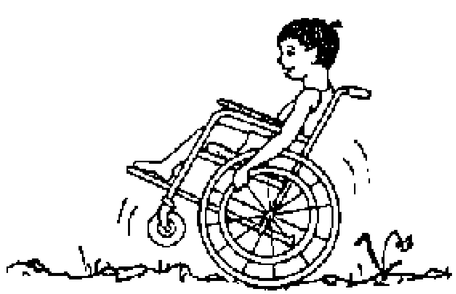
Note: The above front-wheel-drive chair not only risks tipping backward, it will lose traction going uphill, The front wheels do not support enough of the child's weight to grip well, so they will slip.

Mounting the rear caster wheel farther back will help prevent the chair from tipping over backwards on an uphill slope. It will also shift more weight over the front wheels and give them better traction. For these reasons, this modified design is included in the book, *Disabled Village Children*. But even when the rear caster is farther back, traction is not good.

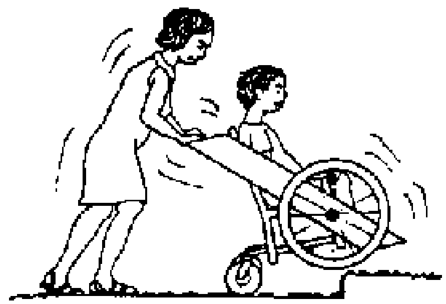
Another problem with front-wheel-drive wheelchairs is that **the rider can not do "wheelies."**



POPPING A WHEELIE TO MOVE OVER ROUGH TERRAIN



In a rear-wheel-drive chair, one of the best ways for the rider to go up curbs or to roll over rough or sandy terrain, is to roll forward while balancing over the back wheels.



In the front-wheel-drive chair, doing "wheelies" is impossible. Even when an assistant is pushing the chair, it is often harder to go up curbs and over bumps.

A rule to consider:

Never follow instructions blindly. Use common sense and creativity.

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CHAPTER 35

A Gravity-Powered Elevator for Wheelchair Accessibility

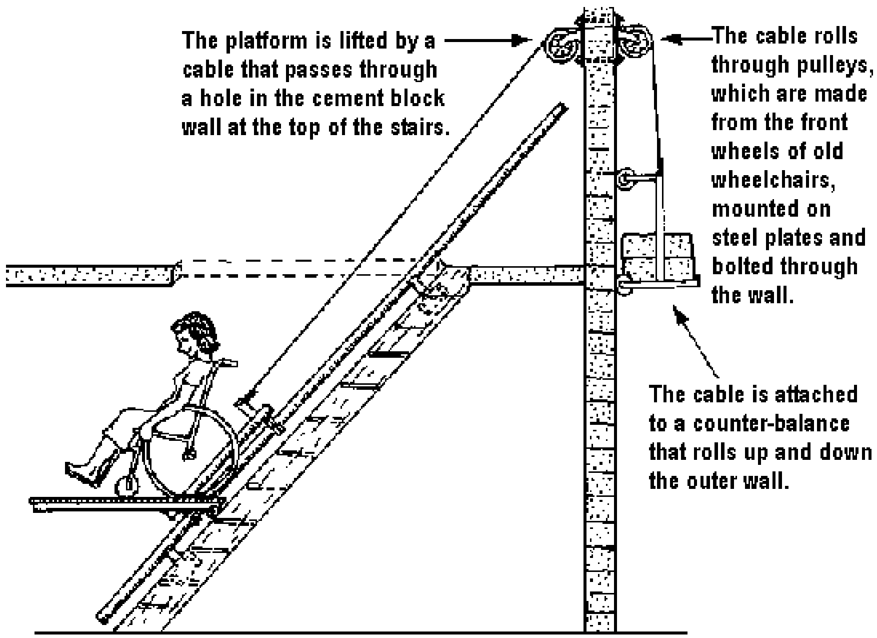
Lack of Accessibility

Getting to the upper floors of buildings with more than one level is, in many countries, a major obstacle for disabled persons, especially wheelchair riders. I (the author) am an advisor to PROJIMO in the village of Ajoya, Mexico, and live on the second floor of a small, two-story cement-block building there. My friends at PROJIMO rightly criticized me for living in inaccessible quarters.

But how could the upper-level of my home be made more accessible to wheelchair riders? The entry is via a steep wooden stairway: little more than a solid step-ladder that leans against a rectangular opening in the upstairs floor. A ramp would be out of the question in the small room with so many steep stairs. The only possibility would be some sort of elevator. But a commercial motorized elevator, or lift - even a small one, designed to glide up a stairway - would be far too expensive. Besides, the supply of electricity to the village is too unreliable. What to do?

A Simple, Home-Made Elevator

To make the upstairs accessible to wheelchair riders, a visiting inventor from Holland, Reinder van Tijen, together with two disabled craftspersons at PROJIMO, Martín Pérez and Marcelo Acevedo, helped to design and build **a simple elevator lifted by gravity**. The elevator consists of a plywood platform mounted on a frame of steel tubing. Welded to the frame are sets of ball bearings that roll along a diagonal pipe attached to the stairway.



- The platform is lifted by a cable that passes through a hole in the cement block wall at the top of the stairs.
- The cable rolls through pulleys, which are made from the front wheels of old wheelchairs, mounted on steel plates and bolted through the wall.
- The cable is attached to a counter-balance that rolls up and down the outer wall.

The counter-balance is weighted with cement blocks, the number of which can be varied so as to match the weight of the particular wheelchair rider. When properly counter-balanced, the elevator glides effortlessly up and down the stairwell.

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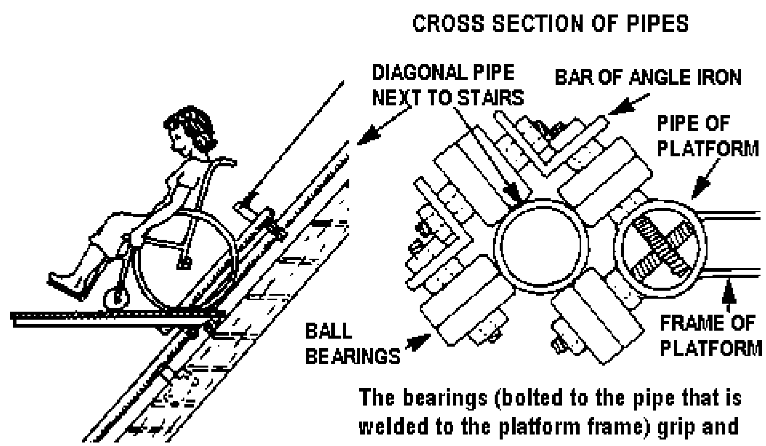
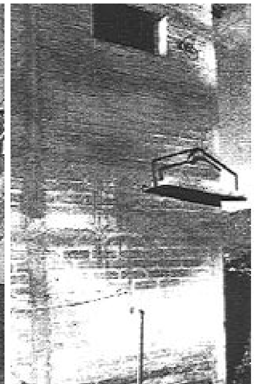
Details of the elevator

A short diagonal pipe welded to the metal frame of the elevator is equipped at either end with 4 sets of ball bearings. These bearings fit snugly around the diagonal pipe next to the stairs.

Another set of ball bearings, attached to the other side of the elevator frame, rolls up and down the edge of the wood plank on the right side of the stairs.




In her wheelchair, Tere rides up the elevator.


The counter-balance on the outside wall is weighted with cement blocks.


roll upon the diagonal stair pipe.

Safety problems that needed solving

The simple elevator worked well. It has now been used by wheelchair-riding visitors for more than 4 years. Since the time it was built, however, visiting engineers warned that the elevator was unsafe. The biggest risk factor, they insisted, was the lack of an automatic locking mechanism to safely hold the platform in place when it reached ground level.

As designed, the platform had to be locked by the rider on reaching ground level. A bolt was slipped through two holes: one in the elevator frame, and one in the diagonal pipe on which the elevator rolled. As long as this bolt was in place before the rider rolled off the platform, there was no problem. But, if he forgot and rolled off without inserting the bolt, the elevator would rocket skyward. This happened once, when a small boy was standing on the edge of the elevator. The platform took off like a rocket. The surprised boy shot upward and fell off into a water tank below. Fortunately, he was unhurt. But if anyone had been on the stairs when the elevator rocketed upward, heaven help them.

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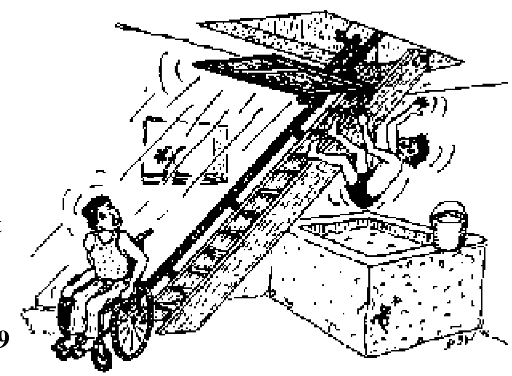
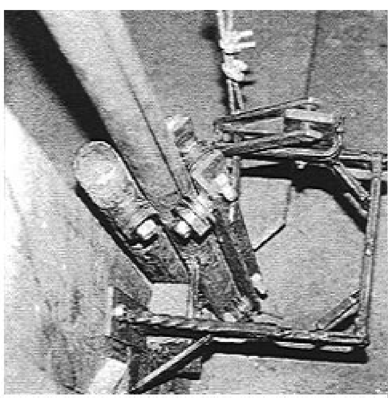


An automatic parking brake for the gravity-run elevator.

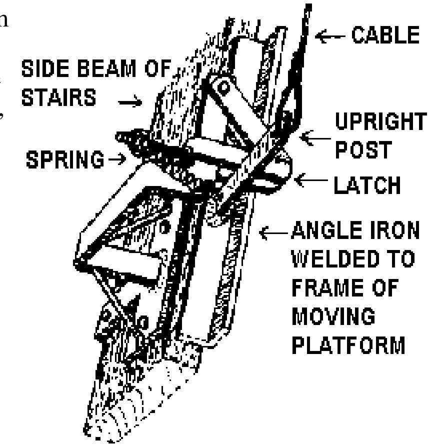

This photo, taken from behind the stairs, looks down at the U-shaped bracket, to


Marcelo installs the safety

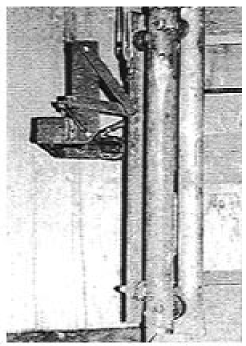
Although visiting engineers insisted that the elevator needed an automatic locking mechanism, none offered a design. Finally, it was Marcelo, the disabled PROJIMO craftsperson, who designed and built a fail-safe automatic locking mechanism for the elevator. He made it out of scraps of iron bar, a spring, and a few bolts.

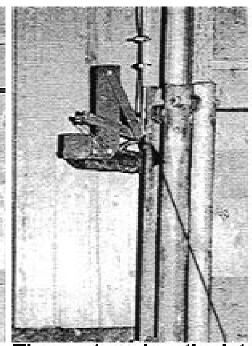
Marcelo modified the design of a latch he built for PROJIMO's main gate, which locks automatically when it swings closed. (He made it after the gate was left open at night and cows ate the banana plants.)

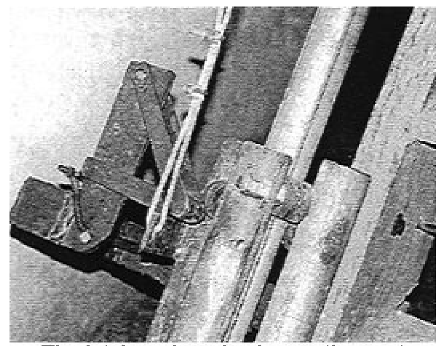
which is attached the automatic latch. latch.



The device is simple. A U-shaped iron bracket is bolted to the side beam of the stairs. To this is attached a V-shaped latch, made by welding flat iron bars. The latch, which pivots on a bolt, is pulled forward by a spring. This latch hooks onto an upright post, welded to the platform frame (the post to which the elevator lift-cable is attached). When the elevator comes down, the post pushes the latch out of the way. Having passed, the latch springs back, hooking onto the post and locking the platform at ground level.


The descending platform approaches the latch.

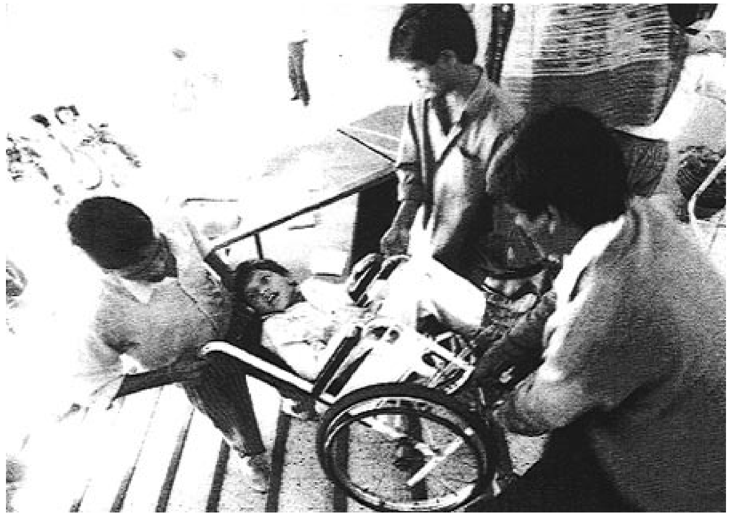

The post pushes the latch to the side and slides past it.


The latch springs back over the post, locking it in place.

The device was tested 100 times and appears fool-proof. The only way to unlock the latch is to put enough weight on the platform so that it lowers a bit more, then push the latch out of the way. As an added safety mechanism, the original bolt-lock can still be used when the elevator is not in use - giving double protection.

In conclusion: Thanks to the warnings of visiting engineers, plus the creative design and building skill of Marcelo, the gravity-run elevator is now much safer.

Stairs Need Not Be So Big an Obstacle When There are Willing Friends

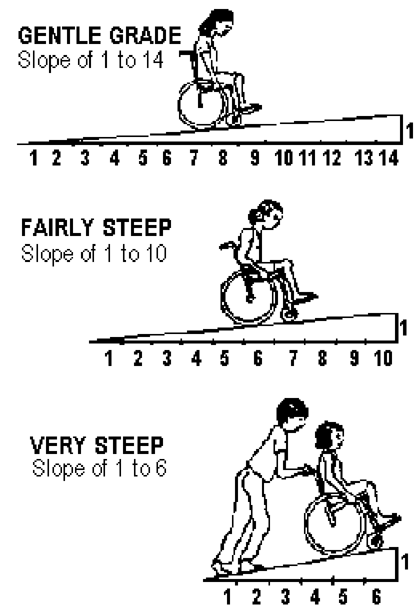


Sometimes a barrier can become a chance for camaraderie. Here friends of a boy in India help him up a long flight of steps. (A lot depends on our culture and point of view. See the story by Mike Miles on page 172.)

Ramps

In many circumstances, ramps are far cheaper and more practical than elevators.

The recommended grade (steepness) of a ramp depends on the strength of its users, and whether they have, or need, assistance. Ramps for public use should have a very gentle slope, so that persons with weak arms can go up them without assistance. But in limited space, a steep ramp may be better than none.



This ramp in a Mexican village clinic was built in a very limited space. The board over the steps lifts out of the way, so that people can use the steps when the ramp is not needed.

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CHAPTER 36

Paraplegics Who Walk Where Wheelchairs Won't Enter (India)

Innovations For, By and With Spinal-Cord Injured Persons in India

Centers for rehabilitation in the United States and many other countries encourage most spinal-cord injured persons to use wheelchairs as their primary way of moving about. Except for a few persons with low-level or incomplete injuries, walking is considered too difficult.

This emphasis on *wheelchair riding with ease* rather than *walking with difficulty* reflects the current trend in rehabilitation. The goal of *maximum function* is placed before *normalization* - even if this means doing some things "abnormally" (differently from how most people do them). Today, many spinal-cord injury self-help groups strongly encourage members to *"Accept yourself as a wheelchair rider and get on with your life."* Individuals are gently discouraged from putting a lot of hope or energy into *"learning to walk again."* Instead, they are urged to **"join in the fight for accessibility and social acceptance of wheelchair riders."**

I was, therefore, surprised by the approach of the rehabilitation center linked with the *Christian Medical College* in Vellore, India, which I visited in 1995 during a UN workshop on "Indigenous Assistive Devices for Disabled Persons." **At the center, many paraplegic persons were being vigorously trained to walk with leg braces and elbow crutches.**

Started in 1934 by a visionary woman doctor who was paralyzed in a car accident, the Vellore Center is recognized as the country's best, most comprehensive spinal-cord injury program. I was impressed, not only by the quality of services and innovativeness of activities, but by its human warmth and convivial spirit. The center's outstanding staff made a point of including disabled persons in the problem-solving process: as friends, co-workers, and equals.

Innovations at the center included a **traditional village**, complete with thatched huts and vegetable gardens. Here, disabled villagers lived and relearned the skills and the **activities of daily living in a typical rural environment**. We saw persons working and moving about there on crutches, or sometimes, crawling with knee-pads - but few used wheelchairs.

At first, I was concerned by the emphasis on walking rather than on wheelchair use. In recent years, India's government has launched a major program of wheelchair production. In cities, at least, increased attention is placed on wheelchair access (though there continues to be a huge unmet need).

I asked the Director: "Why such a strong emphasis on walking? Wouldn't it be more realistic to teach most paraplegic persons to use primarily wheelchairs?"

"Not at all!" he said. "Most spinal-cord injured persons who pass through our center come from remote villages, where wheelchair use is almost impossible.

"You will see for yourselves when we go to a village this afternoon."

He was so right!

To reach the village of a paraplegic man in rural India, a wheelchair-riding United Nations coordinator of our group had to be helped across streams and through sand, mud, and high grass. (David Werner is on the left.)

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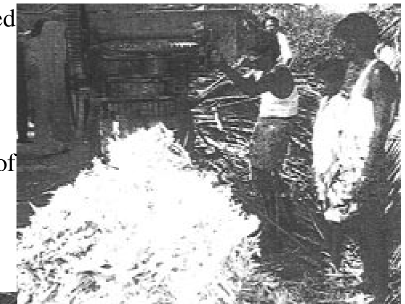
Visit to an Independent Sugar-Cane Farmer Who is Paraplegic



We visited a paraplegic man on the outskirts of a small village. To reach his homestead, we drove the last 2 or 3 miles over a narrow, muddy, rutted country road, difficult to travel even in a Jeep. For the last 200 yards, we had to travel by foot. We quickly realized the limitations of a wheelchair in such places.

On arrival, we made our way through a muddy field behind a large mud house. There we saw a man standing next to a small, rustic gasoline-motor-run sugar-cane mill. He was skillfully pushing armfuls of green cane into the rolling jaws of the machine. Helping him was a boy who, we learned, was his son. We had to look twice to realize that the man was disabled. He wore full-leg braces and arched his body backwards to stand and work with both hands, without having to support himself with his crutches.

RAM, the man at the mill, saw us approaching. He bounded over a pile of milled cane and greeted us warmly. He was dark, muscular, and had a look of uncrushable self-assurance. He appeared to be in excellent health (better than many people in India's hunger-ridden rural areas).

We observed Ram doing a variety of daily chores, ranging from clearing pathways to leading his cow to pasture across the narrow dikes of a rice field. Totally self-sufficient, he provided for his wife and children through his own hard physical labor. He had the innovativeness of one who, since childhood, has lived in a difficult environment where dexterity and creative ingenuity are essential skills for staving off hunger and for survival.

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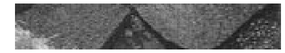
A pit latrine. Ram's innovations included a pit latrine with a wooden toilet seat (unusual for rural India, where the custom is simply to squat). He had built it next to a cement-covered mud-brick water trough. (The pit was over 2 meters deep, in order to avoid contamination of the surface water that fed the trough, which ran through a shallow ditch from a spring, 200 yards away.)

Home-grown castor-oil catheter lubricant. Ram had also found a way to catheterize himself at low cost. Like most spinal-cord injured persons who lack normal bladder control, to drain out urine he needed to pass a catheter (clean rubber tube) through his penis into his bladder every few hours.

Rubber catheters can be cleaned and reused hundreds of times (see Chapter 25, on catheterization). But for each use, they need to be lubricated (oiled). And commercial medical lubricants - such as *KY Jelly* - are expensive.

To save money, Ram had stopped using costly medical lubricants and had begun to use castor oil. But he soon

Ram stands in front of castor trees he planted to make castor oil for lubricating his catheters.



learned that commercial castor oil was contaminated, causing repeated urinary infections. So he planted his own castor trees, harvested the beans, and pressed them carefully under clean conditions to extract the oil. With this clean home-made oil, he explained, he now had almost no problems with urinary infections.

A two-rear-wheel-drive tricycle. For most of his farm work, Ram moved about with full-leg orthopedic braces and crutches made at the rehab center in Vellore. But for travel into town, he used an "all terrain tricycle" that he had designed and built with help from a local welder.

Most hand-powered tricycles made in India have front-wheel-drive, and they are therefore useless in mud and sand. The front wheel has little traction and tends to slip because the person's weight is mostly over the back wheels.

But Ram's tricycle was different.

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Ram's tricycle has 2 hand cranks (adapted bicycle pedals), one on either side. With bicycle chains and sprockets, they power both back wheels.

The steering mechanism consists of a bar extending back from a bicycle fork that holds the single front wheel. When traveling on a fairly hard, flat roadway, Ram can steer with one hand and pedal the chair with the other (one wheel drive). For two-wheel-traction in mud or sand, he can pedal with both hands. But that means he must let go of the steering rod.

In order to keep the chair moving ahead in a straight line when he is not holding the steering rod, Ram improvised a spring device on the steering shaft of the front wheel fork. (See photo on left.)

The 2 springs persistently push the front wheel into a straight position. When Ram comes to a curve in the path, he lets go of one pedal just long enough to get around the curve. When he lets go of the steering rod, the front wheel automatically straightens.

Another advantage of this two-hand rear-wheel-drive tricycle (compared to one-hand-drive ones) is that for long distances it is less tiring to use. The rider can provide power with both arms at once, or use only one arm while resting the other.

(For more ideas on hand-powered tricycles, see Chapter 31. For a "4-wheel drive" all-terrain tricycle, see the drawing at the bottom of page 343.)

Observing the innovative problem-solving skills of rural disabled persons like Ram made a deep impression on the visiting rehabilitation specialists and technicians. By the end of the 10 day workshop, many declared they would work more as "partners in problem solving" with disabled clients, and encourage them to design or improve upon their own devices and solutions.

The visiting professionals gained greater respect for the creativity and abilities, not only of disabled people, but of *poor, unschooled, disabled people*. And that was a big step forward.

One of the participants in the UN workshop tries out Ram's tricycle. Hand-pedals that power both rear wheels make it an "all terrain vehicle."

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PART FOUR
WHEELS TO FREEDOM

CHAPTER 37

Martín Builds a Jointed Gurney to Keep His Hips from Stiffening

MARTÍN Pérez, since he was 10 years old, lived on the streets in Culiacan, the capital city of the state of Sinaloa, Mexico. He survived by stealing, doing odd jobs, and trafficking drugs. At age 15, as a result of a gang dispute, he was shot through the spine and became paraplegic (paralyzed from the middle of the back down). Upon his release from the hospital, he was sent to PROJIMO.

On his arrival, Martín was near death from a urinary infection and pressure sores that had developed in the hospital. He was angry and depressed, but had the will and spirit of a survivor.

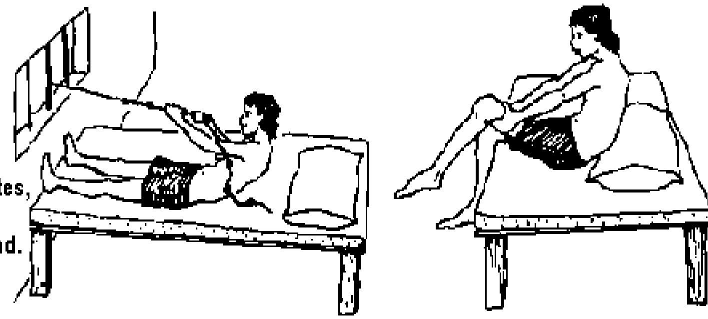
As is usual in PROJIMO, other spinal-cord injured persons took over the management of Martín's urinary problem and pressure sores. In the wheelchair shop, they built a wheeled cot, or gurney, so that he could be active while lying on his stomach, and so his sores (on his backside) would heal.

Frozen hips. Martín recovered his health, and his sores healed in record time. But a new problem was developing. His hip joints were beginning to *ossify* - in other words, the flesh around the hip joints was beginning to turn into bone.

Jaime rides a gurney because his hips do not bend. Here he paints the frame of a tricycle trailer. (see page 201)

This problem, called *myositis ossificans*, occurs occasionally in spinal-cord injured persons. It happened to Jaime, a worker in PROJIMO's wheelchair shop. Because his hips are solidly fused into a straight position, Jaime works while lying on a gurney (see photos on pages 195, 200 and 247).

There is a debate among specialists as to what to do when *myositis ossificans* starts to develop. Some recommend very limited motion of the hips, in the belief that movement causes irritation and speeds the deposit of bone. Others argue in favor of aggressive range-of-motion exercises, to try to stop the joints from freezing up. Martín learned that Jaime had not exercised during the time when his hips became ossified. Therefore - at a stage when Martín's hips had almost no movement left - he set about **exercising to bring back flexibility**. Every morning his hips were so stiff he could barely move them. But he would diligently exercise for an hour or more to recover lost range of motion.



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With his persistent exercise program, Martín managed, in time, to regain complete range of motion of his hips. Nevertheless, every morning his hips would partially "freeze up." For years, he had to keep up his morning exercise routine to maintain flexibility.

Martín's great strengths and weaknesses. In PROJIMO, Martín's presence was a mixed blessing. On the negative side, he had a violent temper which sometimes led to acts of physical violence. He also used drugs (mainly marijuana) on the PROJIMO grounds, even though drug use was prohibited by group decision. He was also openly critical of weaknesses in the organization and its leadership, which caused his own errors to be less tolerated. (Eventually he was expelled.)

On the positive side, Martín developed into an extremely innovative and creative wheelchair builder. He solved design problems in the Whirlwind wheelchair that disability engineer Ralf Hotchkiss had struggled with for years (such as a very simple mechanism to adjust the angle of the footrests).

Ralf was so impressed with Martín's abilities that he invited him to live in his home and to work in his shop for a number of months. Martín even became a teaching assistant in Ralf's course in rehabilitation design and engineering at San Francisco State University, in California.

Also on the positive side, Martín was very friendly and helpful to some of the neediest disabled children at PROJIMO. Whenever they needed help with their aids or equipment, they went to Martín, who would always help them in a warm, personal, and effective way.

A Jointed Gurney for Post-Surgery Recovery

Martín was sometimes too active and hard working for his own good. He had begun to use a wheelchair before the last pressure sore on his backside had healed. As a result, the sore - although it had healed except for a small opening on the surface - had formed a large and stubborn cavity underneath. Periodically this cavity became infected. Surgeons from *Interplast* (International Plastic Surgery) who examined Martín decided he needed surgery to repair the deep sore. They offered to do the operation free of charge, in Stanford, California.

Martín's biggest worry was the post-operative period. The surgeons told him he would need to lie on a special "air bed" for 6 weeks, to allow healing. But Martín - who knows his own body well - feared his hips would freeze up forever if he lay flat for so long and could not do his daily bending exercises. In order to maintain flexibility, he felt that **during the post-surgery period he needed to be positioned at different and changing hip angles**. He told the surgeons he could make a jointed gurney with adjustable hip and knee angles to use post-operatively. But the surgeons were skeptical.

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The surgeons doubted that Martín could make a satisfactory gurney. And if he did, they doubted that he would be able to lie on it face down all day long.

But Martín was persistent. The doctors decided to test him. They insisted that he spend three days and nights continuously on the gurney, to prove that he could do it without complications. Martín did this successfully, and the doctors at last agreed to let him use the gurney following surgery, instead of being on the special hospital bed.

Excellent results. To the doctors' amazement, on his jointed gurney Martín's post-operative recovery went remarkably quickly and well. They observed that Martín was very active on the gurney. They agreed that such activity increased blood circulation, which probably speeded surgical healing. (This finding is consistent with other observations by the PROJIMO team on the healing of pressure sores, after surgery and otherwise. See "Medical Treatment of Osvaldo's Pressure Sores," page 252.)

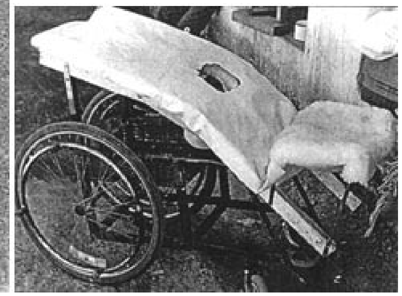
THE GURNEY

The flexible gurney that Martín made for his post-surgical recovery period was built on top of a standard donated wheelchair. The hip and knee angles could be easily adjusted by hand. He upholstered each section of the gurney with water-resistant vinyl (plastic cloth).

The above photos show Martín trying out his new gurney, and the gurney alone in 3 of the many different positions to which it can be adjusted.

Different Kinds of Jointed Gurneys

Other jointed gurneys have been custom-built at PROJIMO and used by persons with a variety of needs. Here is a gurney for a boy, **DANIEL**, who is paraplegic due to tuberculosis of his spine. When Daniel came to PROJIMO, his body, hips and knees were contracted in a sitting position, and he had severe pressure sores. Therefore, the team built for him an adjustable, jointed gurney that could gradually straighten him out.

The gurney has a hole in it through which the boy can pass urine - with or without a catheter - into a bag or bottle. (Spinal-cord injured persons usually lack urine control. See page 147.)

In contrast, the next chapter describes a jointed gurney that was built for a boy (Osvaldo) to gradually bend his hips and knees, which had stiffened in an extended (straight) position.

Additional information on designs for wheeled cots or gurneys can be found in the book, *Disabled Village Children*. Also see the next chapter, pages 246-248.

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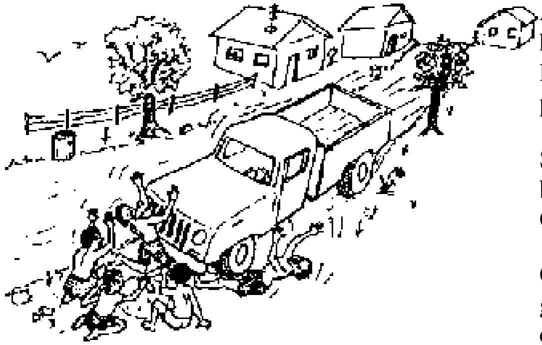
CHAPTER 38

Osvaldo:
A Triplegic Boy with Many Challenging Needs

OSVALDO's *childhood was like that of many boys in a poor urban community. He lived with his ailing mother on a hill on the outskirts of Culiacan, the state capital of Sinaloa, Mexico. His father had abandoned the family years before. His mother worked in a factory, for wages so low that sometimes there was little to eat. Osvaldo went to school, but he often skipped classes to do odd jobs or to play.*

When he was 13 years old, an event happened that drastically changed Osvaldo's life. He was playing with friends on the roadside outside the family hut, when a truck parked at the top of the hill, and the driver got out. Then the hand-brake failed, and the truck rolled down the steep dirt road toward the children at play. It suddenly pitched off the narrow road, straight into the children. One child was killed, four were injured. Because the driver had not been in the truck (and had slipped the police a bribe) he was not held responsible.



After he was hit, Osvaldo - dazed and bleeding - tried to stand up. But he could not move his legs or his right arm. Neighbors took him to the hospital. The doctors found **his spinal cord was crushed at mid-back level** (T6). He had a double fracture of his right leg, above and below the knee. His right shoulder was broken and dislocated, with nerve damage that left his **right hand and arm paralyzed**.

So it was that, at age 13, Osvaldo became *triplegic* (paralyzed in 3 of 4 limbs). He had **lost all movement and feeling in his lower body** and had **no urine or bowel control**. In the hospital his broken spine was stabilized surgically with metal rods. (Fortunately, Osvaldo's mother had social security insurance which covered most of the medical expenses.)

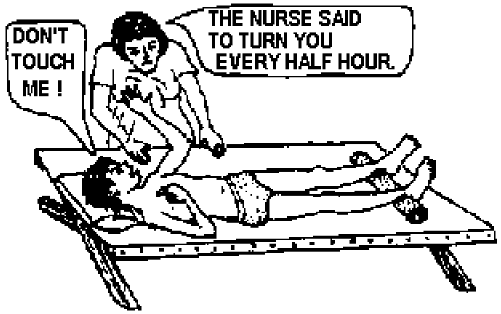
On his release from the hospital, Osvaldo was taken by ambulance to his home. Unfortunately, neither he nor his mother had been given instructions about prevention of pressure sores and urinary infections. So, day after day, Osvaldo lay on his back on a burlap cot without moving. A month later, when a nurse made a home visit, she found that his back, buttocks, and heels were covered with **pressure sores**. The hospital then provided an "egg crate" foam mattress, and a nurse instructed the boy's mother to "Turn him frequently from side to side."

But this was easier said than done, as his mother soon discovered. Osvaldo had sunk into **severe depression which expressed itself as anger**, directed mostly at his mother. His paralyzed right hand was extremely sensitive: it gave him unbearable, burning pain, especially when it was moved. He rested it over his chest without moving it for weeks and months. In time, his right arm became stiffly fixed in front of him. **He was so afraid of having his painful hand touched or moved that he refused to let his mother get near it.** Whenever she tried to move him he would weep and protest. Using his good left arm, he fiercely fought off her attempts to turn him on his side. Because of his lack of urine and bowel control, she had a hard time keeping him clean.

PROJIMO TO THE RESCUE

In November, 1991, on a visit to the capital city, two disabled workers from PROJIMO learned about Osvaldo and visited his home. Five months after his accident, the boy was near death. Emaciated, anemic, and very depressed, he had deep pressure sores, a urinary infection and chronic fever. His doctors had not stressed the importance of drinking lots of water to reduce the risk of urinary infection. Adding to the danger, they had not changed him from a permanent catheter (urine-draining tube) to intermittent catheterization (see page 147). His dark urine had so much crud in it that the catheter often clogged. His pressure sores, which his mother did her best to clean and bandage, were infected and had black necrotic (dead) areas.

The worst sores were on the back of his ankles. They formed after the visiting nurse - worried about the sores on his heels - told his mother, "Keep a rolled-up towel under his ankles." His mother had carefully followed the nurse's orders. Four months later (when the PROJIMO workers visited the home) deep sores had formed where the towel was still obediently positioned. The sore under the left ankle was so deep that it bared the Achilles tendon.



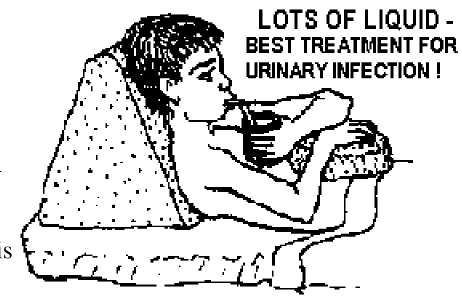
This was a powerful lesson for the PROJIMO workers. They saw the danger of simply giving cookbook-like instructions without explanations. On the contrary, it is important to:

Help people to **fully understand the reasons** for doing things, so that they are able to **make well-informed decisions**, based on their own observations and changing needs.

Further complicating Osvaldo's condition was his delicate, often angry mood, his fear of pain or injury, and the excruciating sensitivity of his paralyzed right hand. Yielding to his tearful protests, his mother had given up attempting to turn him onto his side or belly. So, for five months he had lain on his back, his pressure sores getting larger and deeper, and his body growing as stiff as a board.

On seeing Osvaldo, the PROJIMO workers felt that - due to the difficult combination of physical and emotional needs - more might be accomplished in their small community rehabilitation center than in the home. They invited him and his mother to spend a while at PROJIMO. At first, Osvaldo was afraid to leave home ... or even to be moved from his cot. But the warmth and concern of the PROJIMO workers gave him a new sense of hope. Gathering courage, he accepted their offer. The next morning, with Osvaldo lying on a foam mattress in the back of a station wagon, the group made the 4-hour trip to PROJIMO.

The Need for a Creative and Loving Approach



The complexity of Osvaldo's needs called for very caring rehabilitation and innovative assistive equipment. His urinary infection and sores required urgent attention. For the former, the team gave him antibiotics and encouraged him to drink **lots of fluids**. However, he often refused to drink, even when we explained its importance. Since Osvaldo's favorite drinks were orange juice and hot chocolate, we pampered him with all of these he could drink. As his urinary infection got better, so did his mood and appetite.

The team put Osvaldo on a **high calorie, high protein, high iron diet**. Improving his nutritional status and blood level would help to heal his pressure sores, and fight off the urinary infection.

Managing Osvaldo's Pressure Sores - and Lifting His Spirits

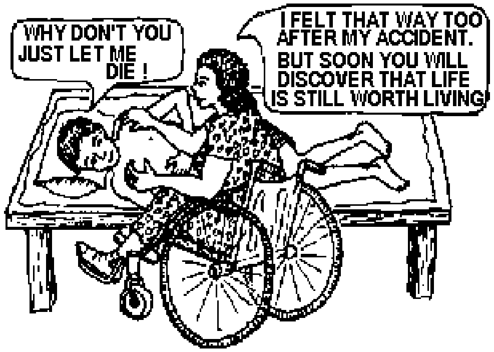
The next job was to find a way of taking the pressure off of Osvaldo's pressure sores. To manage the sores on the back and buttocks, PROJIMO usually builds a gurney, or trolley (narrow wheeled bed), on which the person can lie face down. That way he can wheel himself around, and energetically work and play. Keeping active not only makes lying face down for long periods more tolerable, but it also stimulates circulation, which speeds healing.

With Osvaldo, however, lying face down was not an easy matter. From having lain flat on his back for months, his entire body had become as stiff as a board. Also, his paralyzed right arm was almost "frozen," with his forearm over his chest. Both the shoulder and hand were so super-sensitive that he would howl even before someone touched them.

The first job was to win Osvaldo's trust and to involve him in the problem-solving process. The team tried to give him a sense of control that would help him overcome his fear. Often, it seemed that **his fear of the pain was worse than the pain itself**. Certainly it made the pain worse.

On discussing Osvaldo's wishes and needs with him and his mother, it became clear that the management of his sores needed **an integrated plan to lift both his body and his spirit**. His various physical and emotional needs needed to be answered in a "whole-person," or holistic, way. The group agreed that the major short-term objectives with Osvaldo were:

- to figure out ways to get the pressure off Osvaldo's sores for prolonged periods and, as soon as possible, to find a way for him to lie face down without lying on top of his stiff, hypersensitive right arm and hand;
- to help him regain flexibility of his hips and knees, so that he could begin to sit: first in bed, and later (after his pressure sores healed) in a wheelchair;
- to correct the foot-drop (contracture of the heel cords) that had begun to form;
- to help him increase the strength and ability of his useful (left) arm - a greater challenge because he had been right-handed;
- to design mobility aids that Osvaldo could move and steer with only one arm;
- to provide a range of enjoyable and useful activities so as to encourage self-care, self confidence, and more independence;
- while doing all of the above, to provide a friendly, understanding, stimulating, entertaining, and adventurous environment - to help Osvaldo pull out of his depression and rediscover joy in life, the will to live, and ability to love.



Talking with Osvaldo was not easy. It took time for him to gain enough confidence in himself and in others to speak seriously. What seemed to distress him most was his sense of powerlessness and total immobility. He feared remaining dependent, not being able to do anything for himself, to move, or to go anywhere without help.

Therefore, **helping Osvaldo learn to do more for himself, manage his personal body functions, and move under his own power** were seen as urgent goals which could contribute to his healing in many ways.

In these pages, we will not describe all the aspects of Osvaldo's rehabilitation - rather we will focus on several of the most innovative aids and activities.

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Innovations For and With Osvaldo

To help meet the various objectives of Osvaldo's rehabilitation - or revitalization - the PROJIMO team designed a number of innovative devices. They will be described here in the order in which they were created and used.

It is important to note that **most of these innovations were developed with the active participation of Osvaldo himself**. In the process, this 13-year-old boy acquired a much clearer understanding of his body, its unusual needs, and how to meet them. He began to rediscover and become friendly with his own mysterious body, and to increasingly take charge of his own rehabilitation and care. Soon he was reminding and guiding his attendants (especially his mother) about how to position him and where to place padding to prevent pressure sores. His testing, criticism, and suggestions for improvements of devices became a valuable part of the innovative process. As he became an active participant in the design of his own equipment, he gained new confidence, lost much of his fear of trying new things, was less fretful, and gradually became again a friendly, playful boy - although strangely perceptive and wise for his age. (He avidly read *Disabled Village Children* and gave suggestions for the rehabilitation of other children.)

AN ADJUSTABLE BED
- To help reduce pressure over sores, bend his stiff body, and prepare him for sitting

Complexity of the problem: Clearly, for rapid healing of his pressure sores, Osvaldo needed to stop lying on his back and start lying on his belly or side. However, the team realized the need to move toward this slowly, at a pace the boy could tolerate and control. Osvaldo was terrified of being shifted to a new position that might trigger the pain in his hypersensitive shoulder and hand. It had taken his last bit of courage just to come to PROJIMO, and the team did not want to push him too hard or fast. In the first days, especially, it was essential that his experience at PROJIMO be as reassuring and uplifting as possible. Therefore the team, together with Osvaldo and his mother, tried to think of ways to reduce the pressure on the sores on his back and buttocks - and to help him regain some flexibility in his hips and knees - while still lying face up.

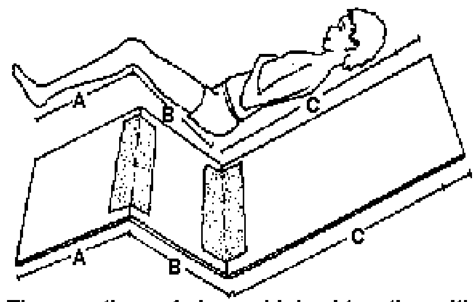
Partial solution: To reduce pressure over the bony areas with sores, Osvaldo was laid on a **double foam mattress**, the lower one thick and fairly firm, the upper one quite soft. To help speed healing, the sores were packed daily with a paste made of **bees' honey and sugar** (see page 156).

From lying flat on his back for so long, Osvaldo's hips and knees had grown so stiff (with extension contractures) that they almost would not bend at all. Bending exercises were introduced. What was needed, however, was prolonged, very gentle stretching. It would have helped to have a hospital bed that could be gradually cranked up into a sitting position, slowly bending the hips and knees. But such a costly item was out of the question.

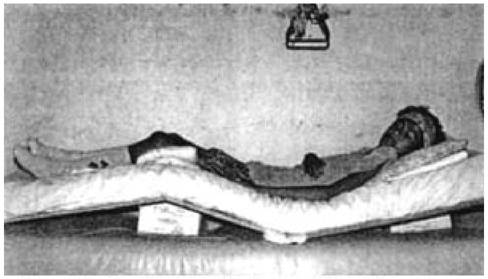
Partial solution: an adjustable, hinged plywood bed board.

Materials: 1 sheet plywood; 2 strips old cloth (about 6 inches wide); white glue.

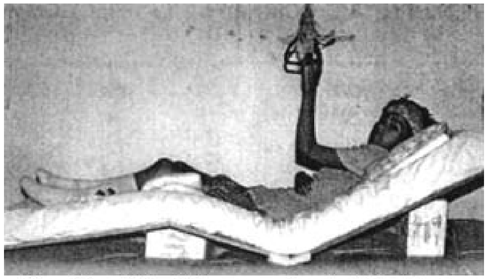
Construction: A piece of plywood the size of the cot was cut in three pieces based on Osvaldo's body measurements (A=feet to knees, B=knees to hips, C=hips to head). The plywood sections were then joined together with cloth hinges made with strips of old towel and white glue.



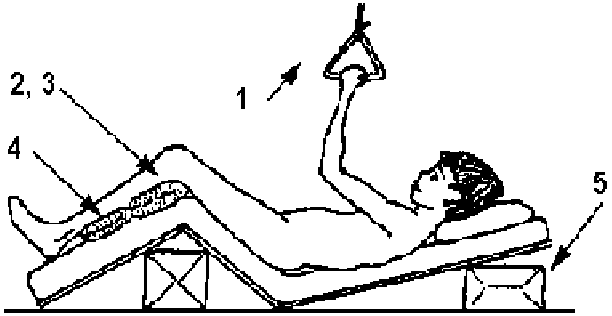
Three sections of plywood joined together with cloth hinges.



Osvaldo, beginning to bend at the hips.

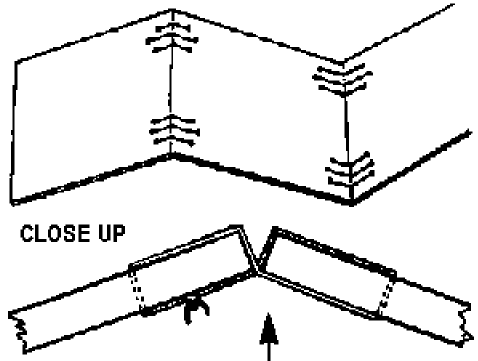


Osvaldo, with a little more bend at the hips.



1. A metal triangle, hanging from a rope over Osvaldo's bed, allowed him to lift himself up periodically with his good arm. This took pressure off his back, and also helped strengthen his arm.
2. By putting padding under Osvaldo's knees, some of the weight could be taken off his backside.
3. This padding reduced the pressure on his buttocks and lower back, where he had some of his worst sores.
4. Padding was also placed under his lower legs, to take pressure off his heels and ankles.
5. By putting boxes of different sizes under the bed-boards, the angle of his hips and knees could gradually be increased.

Results: Flexibility of Osvaldo's body returned surprisingly quickly. Within a few weeks, both his hips and knees flexed to almost to 90 degrees. Also, being able to move into a partly sitting position allowed the boy to do more things more easily (eat, read, draw pictures, and take part in what was going on around him). His disposition improved accordingly. And his pressure sores began to heal.



Cord laced in figure-8 for easy bending, as seen in this cross section.

Technical problem: With repeated removal and replacement of the hinged plywood bed-board between the two foam mattresses, the cloth hinges began to tear loose.

Solution: **hinges made of thin cord.** As an experimental alternative, hinges were made using cord (thick string). The cord passes through small holes in the edges of the plywood sections.

Results of cord hinges: These hinges were as quick and easy to make as the cloth hinges, and they could be used at once (whereas several hours of drying time were needed before the cloth-and-glue hinges could be used). The cord hinges are stronger and hold up longer than the cloth hinges (although this clearly depends on the relative strength of the cord, the cloth, and the glue).

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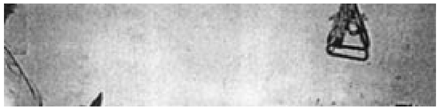
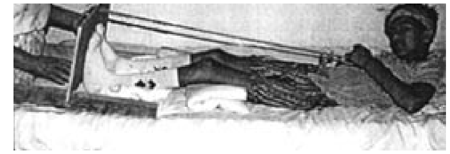
A SIMPLE AID FOR ACTIVE CORRECTION AND PREVENTION OF FOOT-DROP, IN BED

The problem: From lying in bed so long, Osvaldo had begun to develop contractures of his heel cords (Achilles tendons). This made it difficult to bring his feet up to 90 degrees. He wanted to do this with the dream of someday standing or even walking - or at least so his feet would be in a good position and he could wear shoes.



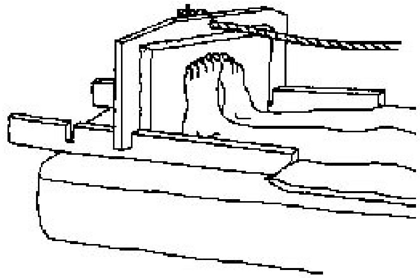
Osvaldo wondered if there was some way he could do the exercises by himself to regain the flexibility of his ankles.

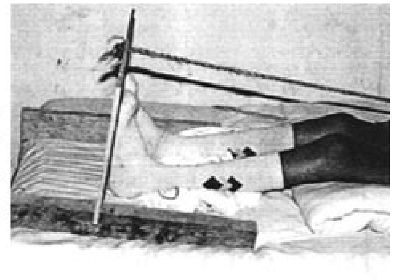


The solution: a flexible foot-board pulled by a rope.

Materials: a short piece of thin wood plank; 2 narrow boards about 2 cm. by 6 cm. by 60 cm. long; a piece of rope (about 1 meter); a piece of dense rubber foam (to cushion the feet).

Construction: Notch wood, drill hole, and assemble as shown.





How it works: The footboard is placed to keep the feet upright (as near to 90 degrees as possible). For his heel-cord stretching exercises, Osvaldo pulled the rope himself.

As Osvaldo pulls the rope, the front ends of the side boards sink into the foam mattress, angling the footboard forward and stretching the feet (and heel-cords).

Results: The device worked fairly well. The hinge-like action, which allowed the foofboard to angle forward more when pulled, was unplanned and recognized only when tried. The device actively involved Osvaldo in exercises to correct and prevent further contractures of his ankles. Moreover, to do the exercises, he had to move his upper body and shoulders somewhat, which he had resisted doing because of his hypersensitive right arm. So the foot exercises were also good therapy for his painful shoulder and arm.

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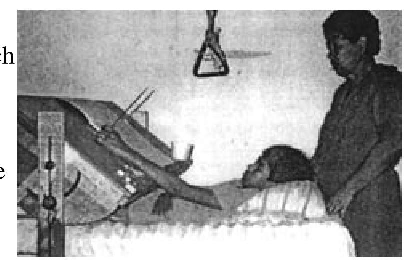
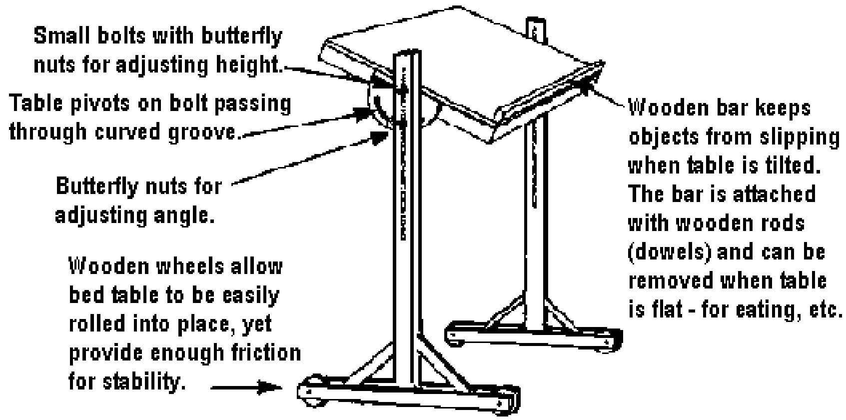
AN ADJUSTABLE BED TABLE



The problem: Osvaldo, who before his accident had been right-handed, needed to develop confidence and skill in using his left hand. He also needed activities to keep him interested and busy during the long periods of lying in a flat or semi-sitting position. For this, he needed a table which could easily be rolled over his bed, and which could adjust both in slant and in height. The group decided that a wooden design, which any village carpenter could make, would be ideal.

Solution: Two of the workers in the carpentry shop (Mario, who is paraplegic, and Rafa, who is quadriplegic) designed and built the wooden table shown below.



- Small bolts with butterfly nuts for adjusting height.
- Table pivots on bolt passing through curved groove.
- Butterfly nuts for adjusting angle.
- Wooden wheels allow bed table to be easily rolled into place, yet provide enough friction for stability.
- Wooden bar keeps objects from slipping when table is tilted. The bar is attached with wooden rods (dowels) and can be removed when table is flat - for eating, etc.

Results: The table was handsome, strong, and it worked well. It was large and solid enough to double as a drafting table. It could also be used as a typing or work table by someone in a wheelchair. This model can be easily made or adapted by a local carpenter. Wooden wheels help keep the cost down. The only welding necessary was to fasten the "wings" on the butterfly nuts. (Ordinary nuts and bolts would work as well, but require a wrench.) For transport, the wing nuts can be removed and the whole table packed flat.

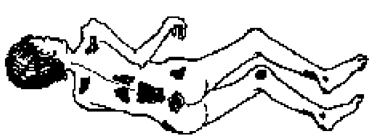
The adjustable bed table made it easier for Osvaldo to do many activities in bed. He took particular pleasure in drawing. He began to confront the challenge of learning to draw and write with his left hand.

Games. Some of the school children who came to visit Osvaldo made a **checker board** for him. While playing such games with other children, often the sign of a smile would creep over Osvaldo's face.

The main disadvantage of the table was its heavy weight and bulky size (as compared to the welded commercial hospital bed-tables that roll in from one side of the bed).


Village children make a checker board to play the game with Osvaldo.

GURNEY (NARROW WHEELED BED) WITH ONE-HAND DRIVE



Problem: To heal his pressure sores, Osvaldo needed to lie face-down for long periods. However, his paralyzed right arm was stiffly contracted over his chest. The arm was so hyper-sensitive that it would take a long time with therapy to regain enough flexibility to place it out of the way so that he could lie face down.

Another problem was how to help Osvaldo regain flexibility (bending ability) of his hips and knees while lying face down. A special gurney could be built for him with adjustable angles at the hips and knees. Actively moving about on the gurney would also stimulate circulation and thereby speed healing of the pressure sores.

But the biggest problem was: How could Osvaldo wheel and steer a gurney with one hand?

Solution: **A one-hand-drive gurney with adjustable hip and knee angles, and with a cut-out section and lower-level table for his paralyzed arm.**

A rectangle was cut out of the bed of the gurney at the level of Osvaldo's right shoulder, so his stiff arm could rest on a small, cushioned table underneath.


Gurney in straight position.


Gurney showing cut out space for the arm, and the cushioned table underneath.


Gurney in bent position. It bends from straight (no angles) to right angles at the hips and knees.


Osvaldo was first placed on the gurney lying in an almost straight position.


The angles of the gurney were slowly adjusted so that, little by little, his hips and knees would bend.

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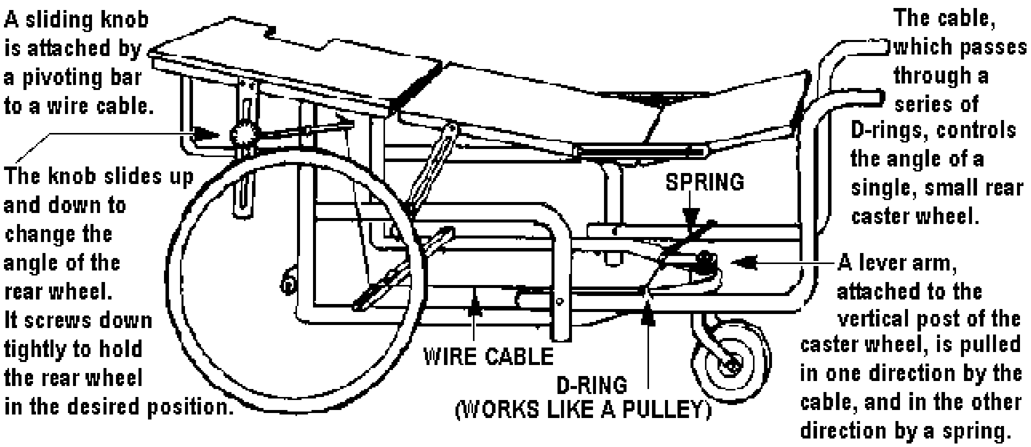
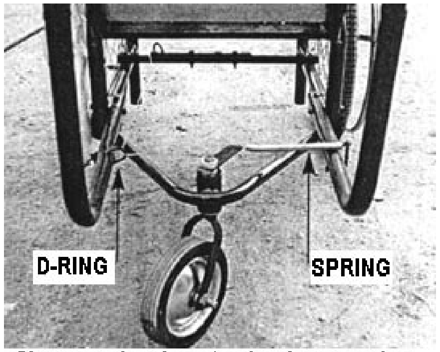
The steering device for the one-arm-drive gurney



- A sliding knob is attached by a pivoting bar to a wire cable.
- The knob slides up and down to change the angle of the rear wheel. It screws down tightly to hold the rear wheel in the desired position.
- The cable, which passes through a series of D-rings, controls the angle of a single, small rear caster wheel.
- A lever arm, attached to the vertical post of the caster wheel, is pulled in one direction by the cable, and in the other direction by a spring.

To move straight ahead, Osvaldo tightens the steering knob to hold the rear wheel straight, and rolls the gurney by pushing the hand rim of the left big wheel. **To make a turn,** he quickly loosens the knob, slides it up or down to angle the caster wheel either to the left or right, and again locks the knob in place. The turn completed, he again moves the knob and locks it in the straight-forward position.

Close-up of hand controls for steering gurney.



Close-up showing steering lever, spring, and cable.

Results: Although it had certain problems and limitations, the gurney was a great success for Osvaldo. Through repeated experimentation, and a flood of complaints and suggestions by Osvaldo, the steering mechanism was gradually improved.

At first, too much force was required to make a right turn, and only a very wide turn was possible. But, by placing the D-ring (pulley) nearest the caster further back to provide a pull at closer to 90 degrees, sharper turns could be made, and made more easily. Also, at Osvaldo's insistence, a rack was added on the front of the gurney to hold a large bottle of water (see page 197). This request by Osvaldo reflected his growing interest in making sure he drank enough liquids to avoid further urinary infections.

248 Jaime, a member of the PROJIMO team, works on Osvaldo's wheelchair. As a paraplegic person who works from a gurney, Jaime well understands Osvaldo's needs. He is a marvelous role model for the younger boy.

At first it was very difficult to place Osvaldo on the gurney and to position his hyper-sensitive arm without hurting him. But after a few days, the arm began to get a little more limber and the boy learned to help position both himself and his arm. Once in position, he was soon able to stay comfortably on the gurney for hours.

As the angles of the gurney at Osvaldo's hips and knees were gradually increased, the flexibility of his joints improved rapidly. Osvaldo soon began to spend much of the time on the gurney with his hips fairly straight and his knees bent up. The elevated position of his feet helped to prevent them from swelling. This, in turn, helped his ankle sores to heal.

In summary:

The gurney contributed to Osvaldo's rehabilitation in a wide variety of ways:

- It helped to heal his sores by removing the pressure on them (by his lying face down). Also, his energetic activity on the gurney improved his circulation, which helped the sores to heal faster.
- It protected his hypersensitive right hand by supporting it on a pillow below his body. But at the same time, his activity on the gurney caused some movement of his delicate arm and hand. He tolerated this because his mind was on other things and he was having a good time. Gradually his hand became less sensitive, so that he cautiously began to move it, to wash it himself, and to gently do exercises to get back flexibility. (Although the hand remained paralyzed, some strength returned in his shoulder, and eventually he started using it as a helping hand.)
- The hinged bed of the gurney helped to correct the extension contractures of his hips and knees, by gradually increasing the bend of its jointed sections.
- With its one-arm drive, the gurney allowed him the freedom of self-controlled and self-powered mobility. This greatly improved his outlook on life and on himself.
- Elevating his feet by flexing the hinge at his knees improved the circulation and decreased the swelling of his feet. (This speeded the healing of the deep sores on his ankles.)
- By encouraging physical activity and more drinking of water, the gurney helped to prevent urinary infection and kidney stones.
- Wheeling himself around on the gurney helped to strengthen his more useful arm, providing therapy that was both functional and fun.
- Altogether, the gurney gave him new self-confidence and improved his state of mind. His greater happiness was due partly to being able to go where he liked under his own power, and partly to his participation in designing and improving his own equipment.
- The role model of other disabled persons who ride and work on gurneys helped a lot.

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A ONE-ARM-DRIVE WHEELCHAIR

Once Osvaldo's pressure sores had healed and he regained enough flexibility so that he could sit, he needed a one-hand-drive wheelchair.

The problem: Hemiplegic (one-hand drive) wheelchairs are manufactured commercially in the United States and in other rich countries. But they are very expensive and are usually not available in poor countries. Also, the drive mechanism is relatively complex and tends to break down quickly on rough terrain. (The problems with these commercial one-arm-drive wheelchairs are further discussed in Chapter 39.)

Occasionally, PROJIMO has a second-hand hemiplegic wheelchair donated from the cooperating hospitals and programs in the United States. But at the time Osvaldo needed one, none was available.

Solution: Like many rehabilitation programs in the Third World, PROJIMO has a big need for an easy-to-build, low-cost, hemiplegic wheelchair. It occurred to the workers in the shop that the same front-wheel steering mechanism used for Osvaldo's gurney might work for a wheelchair.

Through a lot of trials and suggestions by Osvaldo, a design was created.

A single front caster was controlled by pulleys and cable to a steering knob mounted on a vertical bracket on the left side of the chair.

Trial construction, trouble-shooting, and improvements. In the early design, the very small D-rings (improvised front pulleys) gave too much resistance and made steering difficult.

In the modified design, larger, smoother-running pulleys were used. This made steering easier.

Pulling on the lock-knob required too much force for Osvaldo (whose back was still painful). Therefore a longer lever-arm was added.

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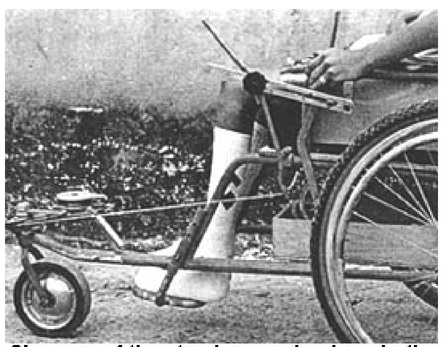
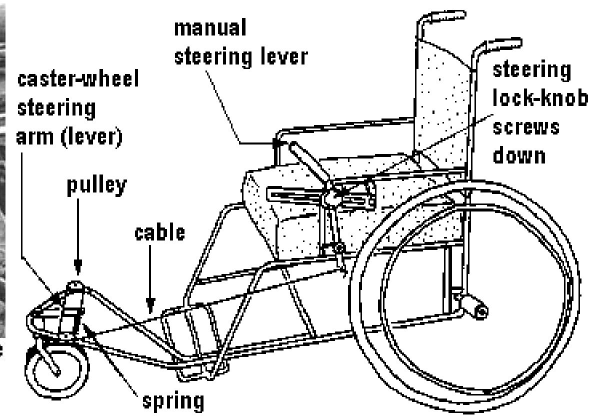
Design details of Osvaldo's wheelchalr:



Close-up of the steering mechanism. In the photo, Osvaldo's hand is on the brake (which is not shown in the drawing).



Results:

After several modifications to make steering easier, Osvaldo found the chair very useful. He learned to steer it with remarkable agility and became relatively independent. The strength in his left arm increased. The removable arm rest on the right side, plus the easy access for his feet, made putting him in and out of the chair relatively simple. He soon learned to help with the transfers, using his left arm.

One disadvantage of this design is its lengthy forward extension to support the steering wheel. This makes moving about in close quarters more difficult (although far less so than the front-wheel-drive tricycles with a bicycle wheel at the front, which are even longer and more cumbersome). On the positive side, the narrowness of the "nose" of Osvaldo's chair, and the small front wheel, make moving about in close quarters somewhat easier.

In conclusion, the Osvaldo one-hand-drive wheelchair provided a relatively low-cost, easily constructed option in situations where standard hemiplegic chairs are seldom available, too costly, and not durable. Although to our knowledge this new wheelchair has not yet been duplicated, we feel it has the potential to help fill the enormous unmet need of hemiplegic wheelchair riders in low-income situations. However, the design still needs to be simplified and improved. One possibility might be to shorten the forward extension to make it easier to move about indoors.

For another, better design of a one-arm wheelchair, see the next chapter (page 253).

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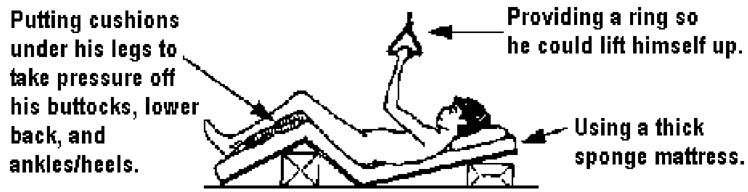
Summary of the Combined Methods of Managing Osvaldo's Pressure Sores

Following his accident Osvaldo lay on his back for 5 months without being turned. When he came to PROJIMO he had 11 pressure sores, extending from mid back to his heels. The largest sores were 2 to 3 inches across. Most were fairly shallow (bone not exposed) and his mother had kept them fairly clean. However, there was some dead as well as unhealthy gray tissue on the surface of the sores. The deepest sore, about 2 inches long, was over the heel cord (Achilles tendon) of his left foot; the tendon was exposed.

Complicating treatment of Osvaldo's pressure sores was his hypersensitive paralyzed right arm, which had become rigidly contracted over his chest. This stiff, painful arm prevented him from lying either face down, or on his right side.

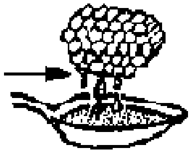
SIX STEPS TAKEN TO PROMOTE HEALING OF OSVALDO'S PRESSURE SORES:

1. Minimize pressure over the sores while lying down. This was done by:



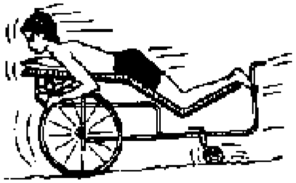
- Putting cushions under his legs to take pressure off his buttocks, lower back, and ankles/heels.
- Providing a ring so he could lift himself up.
- Using a thick sponge mattress.

2. Adequate cleaning of the sores; treatment with sugar and honey.



3. Wheeled mobility while lying face down, with the feet up (until the sores heal).

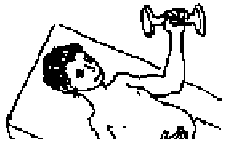
4. Lots of activity to speed up circulation, which causes faster healing.



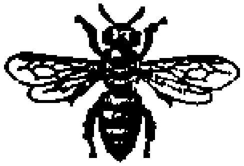
5. Food rich in calories, protein, and iron to strengthen the body and blood, to speed healing.

6. Management of the boy's overall health, especially his urinary system.

7. Strengthening the good arm and increasing his ability to change his position.



MEDICAL TREATMENT OF OSVALDO'S PRESSURE SORES



Treatment involved **daily washings**, at first brisk enough to remove dead flesh. Once the healthy red flesh was exposed, cleansing became quite gentle so as to avoid damage to the newly forming tissues. After cleaning the sores, a paste of **bees' honey mixed with sugar** was applied to the sores and covered lightly with gauze (see page 156).

Results: With this treatment program, combined with the management techniques reviewed on page 251, the sores healed remarkably fast. Even the deep sore over Osvaldo's heel healed in 3 weeks. The team feels it was the combined actions of treatment and management that led to rapid healing. Surely the change in Osvaldo's attitude made a big difference. He began to oversee and take responsibility for his own care, advising his mother and other attendants about how to place padding to relieve pressure over bony areas, and asking to be turned or moved after a time in one position. His increased physical activity also probably contributed to his quick healing, as did the many hours he spent each day lying face-down on his specially designed gurney.

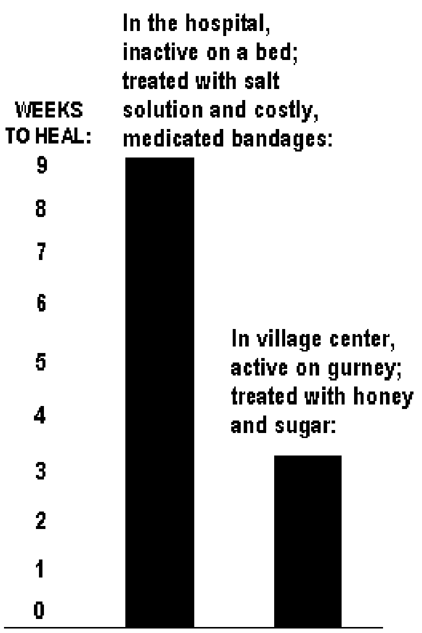
Comparison of PROJIMO's methods with hospital treatment of Osvaldo's pressure sores.
The steel rods surgically placed in Osvaldo's back after his accident came loose, and had begun to poke through the skin. To remove the rods, Osvaldo was taken to an orthopedic hospital in California. During the 2-day drive, a new small pressure sore formed over his sacrum (bottom part of the spine). In the hospital, *Duoderm* (a costly, medicated, absorbent bandage) was put over the sore, and Osvaldo was placed in bed for 24 hours a day. He lay on his back on a special air-flow mattress run by an electric air-pump, so that the pressure over each small area of the body was constantly changing.

In the hospital, with all this costly treatment and equipment, the boy in his space-age bed was deprived of all choice or responsibility for his own care. His pressure sore - smaller and more superficial than ones that had healed in 3 weeks at PROJIMO - took over 2 months to heal.

Ironically, from lying flat on his back for so long in the hospital, Osvaldo's knees and hips were again becoming rigid. A physiotherapist, attempting to restore flexibility, used too much force and broke his right leg. With his leg in a cast for weeks, a new deep pressure sore formed on his right heel. Again, it took over 2 months to heal. During all these months in the hospital, Osvaldo's anger, hostility, and depression - which he had gradually been overcoming - re-emerged. The nurses were at a loss for knowing how to get him to cooperate.

Comparing results of Osvaldo's management at PROJIMO with those at this modern orthopedic hospital, it appears that the comprehensive, action-oriented, *whole-person* approach used at the village center was relatively successful - at least for the healing rate of pressure sores. The rapid healing, achieved with Osvaldo's sores has occurred with many (but not all) persons attended at PROJIMO. More comparative study is needed.

COMPARISON OF HEALING TIME OF SIMILAR PRESSURE SORES ON OSVALDO'S BACKSIDE



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CHAPTER 39

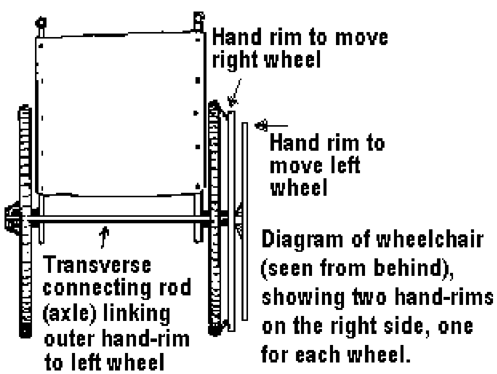
A One-Hand-Drive Wheelchair for Che: A Challenge for Martín

CHE was a policeman until the fateful night he was shot. He and his drinking buddies had decided to play "Russian Roulette," a deadly game where men point a six-shooter pistol with just one bullet in it at each other's head, pull the trigger, and see who gets shot first! Che lost. The bullet left him paralyzed on the left side of his body (hemiplegic).

Luckily, Che's mind and speech were unaffected. He was given a standard wheelchair. But with the use of only one arm, he needed assistance to go anywhere.

Che spent months at PROJIMO for rehabilitation and to learn new skills. A commercial one-arm-drive wheelchair from the United States had been donated to the program. Che loved it, and tried to go everywhere in it. But it kept breaking down.

Commercial one-arm-drive wheelchairs always break. Factory-made hemiplegic (one-arm-drive) wheelchairs are very expensive and seldom seen in poor countries. They have design problems which limit their usefulness. They are built for smooth hospital floors, not village paths. On rough terrain, they repeatedly break - and are hard and costly to fix.



This commercial design is nothing like Osvaldo's one-arm-drive chair made at PROJIMO (see page 249). In the commercial chair, the rider delivers power to both rear wheels with one hand. The two hand-rims, one next to and slightly smaller than the other, are mounted on one side of the chair. One rim is fixed to the wheel on that side. The other is connected by a central axle (transverse rod) to the opposite wheel. To move straight ahead, the rider grips both hand-rims at once. To make a turn, he pushes just one hand-rim.

The weakness of the commercial chair is that the axle that transfers power from one side to the other is too thin. It passes (on ball bearings) through the center of the wheel hub on the near side, and is welded to the hub on the far side. Unfortunately, the axle cannot be replaced by a thicker, stronger one because of the small hub-hole it goes through. When modestly stressed, the fragile axle *breaks.*

Need for a Rugged, Low-Cost, One-Hand-Drive Wheelchair. PROJIMO sees a lot of persons who need a one-hand-drive wheelchair. These include folks who have had a stroke or suffered a head injury (like Che), and children with "hemiplegic" cerebral palsy.

Osvaldo's chair with front-wheel steering allowed him to move about town independently and helped him to recover self-direction and the will to live. The design was simple, low cost, and fairly easy to make, But that chair had one big disadvantage. Like hand-driven tricycles, it took up a lot of space. Indoors, it was cumbersome. There was a need for a one-arm chair that was cheap, road-worthy, and compact.

Martín Pérez Designs a Stronger One-Arm-Drive Wheelchair

MARTÍN, the paraplegic wheelchair builder whose gurney is featured in Chapter 37, was aware of the need for a reliable, one-arm-drive wheelchair. Time and again, he had welded and tried to strengthen the weak axle of Che's commercial chair. He also realized that, if the power-transfer mechanism broke while the rider was climbing a steep ramp or trail, it could be dangerous.

Ralf Hotchkiss examines the one arm drive wheelchair which Martin is building. The 2 hand-rims are on one side and can be powered together or independently with one hand.

During Martín's visit to California, while recovering from surgery, he stayed in the home of wheel-chair designer, Ralf Hotchkiss. When Ralf was away teaching, Martín used Ralf's workshop, which is beautifully adapted for working from a wheelchair (see page 195). One day, Martín began to design and build a one-arm-drive wheelchair that would be compact and low-cost, yet strong.

In building the wheelchair frame, Martín followed Ralf's basic Whirlwind design. **For the one-arm-drive mechanism, he used features from the commercial design, but with a much thicker and stronger transverse rod (axle)** to transfer power from a hand-rim on one side of the chair to the wheel on the far side.

Testing the strength of the new mechanism. When the chair was done, Martín and Ralf tested the strength of the one-arm-drive mechanism. They hooked a spring scale to the far wheel, and with a block-and-tackle put increasing force on the hand-rim that powered it. To their joy, Martín's heavy-duty axle-rod withstood over 200 pounds of force before it broke. This is much stronger than the commercial hemiplegic system (which breaks at about 30 pounds of force).

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