



Newsletter from the Sierra Madre #59

October, 2007



PROJIMO Community Based Rehabilitation Program

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

**IMPORTANT: PLEASE READ
BACK COVER NOW!**

HEALTHWRIGHTS

Workgroup for People's Health and Rights

PROJIMO Skills Training and Work Program

run by disabled youth in rural Mexico (Duranguito)

For three weeks in February and March 2007 David Werner visited South Africa at the invitation of the Western Cape Association for Persons with Disability (WC-APD). During his 3-week visit he facilitated a series of seminars and workshops on Community Based Rehabilitation, first in the city of Cape Town, then in outlying areas in the Western Cape Province. David had an opportunity to visit the homes of some of the people with disabilities assisted by APD, and witnessed the grinding poverty and powerlessness that still oppress the majority of South Africans, despite the celebrated liberation from the apartheid regime that was achieved, by the democratic elections in 1994. Here David describes the continuing socioeconomic polarization in South Africa, and the challenges it creates for those striving for rights and opportunities of people with disabilities.

SOUTH AFRICA'S UPHILL BATTLE FOR EQUITY AND HEALTH

A report by David Werner on workshops facilitated with the
Western Cape Association for Persons with Disability
February—March 2007

Two Worlds Side by Side

Despite the official end of apartheid in 1994, the nation remains divided into two worlds: the haves and the have-nots. Nowhere is this divide more glaring than in the fast-growing city of Cape Town. The picturesque coastal area of the city is festooned with luxurious housing that rivals that of Palm Beach in Florida, or the French Riviera. The affluent consumer lifestyle of this predominantly white neighborhood—complete with manicured golf links, private yachts, backyard swimming pools, and bicycle marathons (with 30,000 spiffily-outfitted riders)—looks for all the world like upper-middle class suburbia anywhere in the so-called First World. Yet the interior of Cape Town is strewn with vast squatter settlements stretching as far as the eye can see. And the abject living conditions of the underclass in rural areas are even more oppressive.

This level of inequity, as one might expect, gives rise to a great deal of crime, despair, drug abuse, and violence. As in other extremely polarized societies, the rich in South

Africa—for their own safety and survival—have had to turn their stately homes into fortified prisons with high razor-wire topped walls, and elaborate burglar alarm systems.

In terms of its total national wealth, South Africa is by far the richest nation in Sub-Saharan Africa. The World Bank now ranks South Africa not as a poor or “developing country,” but as a “middle

income nation.” It has a GDP (gross domestic product) per capita of over US\$10,000: higher than some countries with a far superior “quality of life” quotient their citizens, such as Cuba or Costa Rica. With a more equitable distribution of the nation’s resources, South Africa would be able to provide adequately for the needs of all its citizens.

The new, socially progressive Constitution of South Africa includes many policies and statutes to protect the rights of the disadvantaged, including guarantees of health care, education, adequate housing, water and sanitation, employment opportunities, and a fair minimum wage. It also includes a comprehensive safety net for people with disabilities, the elderly, and others with special needs. But for diverse reasons—including pressures from the international market system—the government has been aggravatingly slow in implementing these constitutional laws and human rights on a large scale. This failure to implement the idealism embedded in the new constitution has led to a great deal of disillusionment and social unrest.



The housing situation is a glaring example of the less than optimal implementation of the ideals of the new constitution. In the vast periurban squatter settlements or “townships,” and in the former “homelands” in rural areas, millions of families live in tiny makeshift shacks made of cardboard, tarpaper, and/or scraps of wood. Little by little, the government’s low cost housing project has undertaken to replace these shacks with small cement block huts. However, progress is slow, and the waiting lists are long. There is no functional provision for giving priority to those in greatest need. On the contrary, families with disabled or chronically ill members too often end up at the tail end of the list—which can mean waiting 4 to 5 years or longer. Bribes and corruption lead to a situation where those with lesser needs often get served before those whose needs are greatest.



This woman, her boyfriend, and daughter with hydrocephalus, live in a squatter settlement on the outskirts of Cape Town.

Ironically, the rather patchwork allotment of housing in the sprawling squatter settlements has tended to create a new level of social division among the underclass. On the small parcel of land provided the new cement block hut, the lucky recipient of the hut often rents space next to the house to one or more destitute families, who put up makeshift shacks, often without electricity, water, or sanitation. The result is that the new government-subsidized block houses tend to stand out like small boats in a choppy sea of improvised hovels.

PRELIMINARY HOME VISITS

The WC-APD organizers had initially planned to include in the workshops only staff members, professionals, and daycare service providers. However, I had insisted

that some of the disabled people and family members (whom they called “clients” and “consumers”) also take full and active part in the workshops so that they could participate in the problem solving processes. Before beginning the CBR workshops, I asked if I could visit the homes and communities of several people with disabilities living in difficult circumstances in order to gain a clearer idea of their problems and possibilities. I also wanted to recruit candidates for the workshops and to explain to them how important their observations and suggestions would be.

On the home visits I was usually accompanied by Lara Strong, a young occupational therapist who works for the central office of the WC-APD in Cape Town. Lara did a wonderful job explaining the complex dynamics of disability-related needs



and services in South Africa. In addition to Lara, on our home visits I was usually accompanied by local social workers from the APD branch programs, who were familiar with the local people with disabilities and their families.

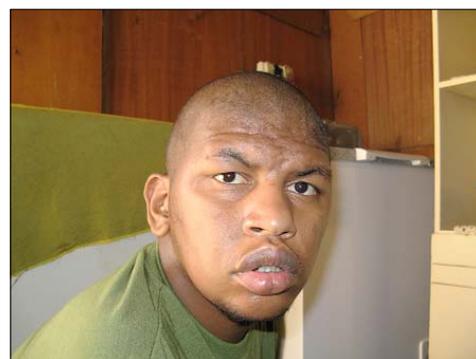
Factors Aggravating Disability

In our visits to people’s homes, it was apparent that one of the biggest obstacles to meeting the needs of people with disabilities is overwhelming poverty. High unemployment, low wages, single parent households, and inadequate support services aggravate poverty. In low-income settlements and rural areas of the Western Cape nearly 60% of households have only one parent, most often a widowed or single mother. And 15% of households have no

adult at all, only children. Adding to the extensive poverty, both through incapacitating illness and the death of breadwinners, is the high incidence of HIV-AIDS.

Clyde’s Story

One of the first homes we visited—in a poor neighborhood on the edge of Cape Town—was that of a bright, friendly young man named Clyde, and his kind-hearted wife, Jacky. Clyde has two brothers with microcephalus (small brains) and “intellectual disability.” The more severely impaired brother, Morne, lives with Clyde, Jacky, and their two young children in a tiny shack made of wood slats and tarpaper.



Morne, one of 2 brothers with intellectual impairment

Morne’s less severely impaired brother, Eric, stays with the father, as do a half-sister of the 3 brothers, her boyfriend, and her child.

The dynamics between the two households are not good, especially those between Clyde and his father. The father refuses to let anyone from Clyde’s shack enter his house; he refuses to let them run a hose or electric line from his house, or to use the toilet. Because the shack doesn’t exist legally, it has no utility rights. This makes the estrangement between Clyde and his father especially difficult for Clyde’s household. A friendly neighbor has let them run an electric line to the shack and allows them to fill buckets of water. But toileting and sanitation remain a big problem. They all use a plastic bucket. At least Morne is more or less bucket trained. But emptying the bucket in the crowded neighborhood is a touchy issue. When Clyde’s father isn’t home, Clyde or Jacky empty the bucket in a sewage sluice on the far side of his father’s house.

The friction between Clyde and his father was triggered by a dispute over the “disability grant” that the government provides every month for the two disabled brothers. The new South African Constitution, at least on paper, is disability friendly. The government provides a very modest monthly stipend (about \$20 US dollars) to householders with a disabled child or family member. While this grant is meant for the needs of the disabled child, often it is a poor family’s sole source of income. As a result, very little ends up directly benefiting the disabled child.

In the case of Clyde’s two disabled brothers, their father—who registered himself as the sole provider (since the mother is dead)—receives two disability stipends from the government. Although his most disabled son, Morne—who requires constant supervision—lives with Clyde, the father doesn’t share the grant money. And he is angry at Clyde for attempting (unsuccessfully) to legally get his fair share of the grant.

The underlying issue is that Clyde’s father is alcoholic. He uses much of the disability grant money to support his habit. Related to the drinking pattern in the father’s household there is a pecking order of violent abuse. Apparently when the father and his daughter’s boyfriend have been drinking, they sometimes beat the daughter. And she, in turn, at times takes out her anger cruelly on her disabled half-brother, Eric. The daughter, who had a black eye when we visited the home, admitted to the APD social worker that one time when the boy didn’t behave, she burned him with a hot iron. “It’s the only way he learns,” she explained. Eric silently showed us the scars.

In welcome contrast to the pattern of violence in the father’s house, in Clyde’s and Jacky’s impoverished shack, the environment appeared to be one of love and understanding. This was reflected in the open, trusting, good-natured attitude of the disabled youth, Morne. Clyde explained how difficult it was to support the family, with his low-paying job. His wife Jacky would like to work, too. But caring for Morne is a full time occupation—and there are no day-care centers that would take him. If

unwatched Morne has a tendency to wander off and get lost. Fortunately, whenever this has happened, friendly neighbors have found him and escorted him back home. But Morne has the mind of a toddler. Jacky is afraid he might be hit by a car, or be molested or given drugs by the local gangs. So she has resigned herself to staying home and caring for Morne.



Teaching Morne takes a lot of supervision and patience, but Morne glows with pride when he is able to be useful.

Both Jacky and Clyde are very kind to Morne, and do what they can to help him learn skills and become more self-reliant. They have even taught him to help with household chores, like sweeping the patio and washing the dishes.

One of the outcomes of this visit was to invite both Clyde and Jacky to the Community Based Rehabilitation (CBR) workshop I would soon be conducting. Both clearly have a lot of good will toward people with disabilities, as well as a lot of practical, hands-on experience. They are the kind of people who, with additional training and encouragement, can become active community rehabilitation workers, visiting other families with disabled children in their neighborhood, and bringing families together to discuss and seek solutions to their common needs.

As it turned out, both Clyde and Jacky took part in the workshop, to which they contributed a lot by sharing their experiences and by making realistic, down-to-earth suggestions. The last I heard, plans were being made to include Clyde as a member of a CBR team with the local branch of the APD.

By the same token, the APD is trying to arrange for Clyde and Jacky to receive a disability grant for Morne. The APD is also investigating the possibility for Clyde and his family to get a government-built, cement block house. Clyde is already on the waiting list for one, but often the delay is 5 years or more. One of the problems is that if and when Clyde does get an improved house, it is likely to be in a new neighborhood where he doesn’t know the neighbors, and where gangs of thieves and drug users are common.

Clyde says that rather than be in a better house in an unfriendly environment, he would prefer to stay in his shack, in a familiar neighborhood where people know and help one other. His biggest hope is to make peace with his father, whom he knows has a positive, caring side. He wishes he could help his father to give up his heavy drinking. The APD, through its social workers, is also trying to work with the father, and help rebuild the family bonds. But it’s an uphill battle.

Internalized oppression and fetal alcohol syndrome.

Because of South Africa’s recent history of apartheid, with its systemic impoverishment and disempowerment of the poor black population, many people still have low self-esteem and a pervasive sense of hopelessness. Alcohol and drugs are a tempting form of escape. Drug dependency, especially among youth, is very common and too often leads to a life of crime and violence to sustain the habit.



In South Africa one of the most common causes of disability in children is fetal alcohol syndrome (FAS). It results from heavy consumption of alcohol by mothers during pregnancy.



Children with FAS tend to be mildly retarded, very restless, have poor attention span, and often strange or inappropriate behavior. They also tend to be underweight, grow slowly, and get sick often.

The health departments and rehab programs such as APD conduct ongoing campaigns to discourage drinking during pregnancy and to educate women about the risk of FAS. But the problem persists—largely because so many women have such a low opinion of themselves and feel it is futile to try to improve their situation. The effects of an oppressive social system on the character structure of the oppressed is referred to as “internalized oppression.” The topic came up over and over again in our workshops.

VISITS TO DAYCARE CENTERS, CHILDREN’S REHAB CENTERS, AND SHELTERED WORKSHOPS

In addition to visiting a number of homes, I was also taken to visit a number of daycare centers, and APD-run centers for rehabilitation and special education. The centers we visited were coordinated by the WC-APD branch programs in the areas of Cape Town, Worcester, and George.

In South Africa there are laws providing the right of all children to education appropriate to their capacities and needs, with the goal of helping every child reach his or her potential. There is also an official policy of mainstreaming disabled children as

much as possible. In reality, schooling possibilities and services for disabled children are few and far between, especially in rural areas. For this reason, the Association for Persons with Disabilities (APD), as a large, non-government organization, makes an effort to have as far-reaching an area of coverage as it can. However, despite the APD’s many branches, and the scores of towns and villages that are reached, the APD is the first to admit that there are many disabled people who are not reached.



Some of the APD centers provide a wide range of services including early stimulation and special education.

The desire to make services available to everybody was one of the motivations behind the WC-APD’s interest in exploring alternative approaches to Community Based Rehabilitation. In the workshops, one of the options that was explored—with examples from PROJIMO in Mexico—was that of conducting disability awareness-raising activities with school children, and then mobilizing the schoolchildren to conduct a village or neighborhood survey, visiting homes to find out how many disabled children (and adults) there are, and which could most benefit from some kind of assistance.

One of the biggest expressed needs of poor families and single mothers with severely or multiply disabled children is for daycare facilities or crèches where they can leave their children in safe hands while they are at work. Therefore one of the main focuses of the APD has been to help set up or support a variety of such centers, ranging from small home-based neighborhood crèches to large multipurpose rehab centers.

On my travels to the different APD branches where the workshops were held, I had an opportunity to visit a full range of these centers, large and small. At best, these centers were well run and provided a spectrum of group and individualized activities for the children (and sometimes disabled youth and adults). At worst, the centers, or crèches, were little more than holding stations where mothers could park their disabled child while she worked.



Some of the most dedicated care providers at the APD centers are local mothers of disabled children.

Daycare Centers

Most of the “care providers” at the small neighborhood daycare centers were local mothers of disabled children who provided services in their homes. Mothers of other disabled children would drop off their children on their way to work, and pick them up again on their way home. Or, in some cases, the APD would provide a van and driver to transport the children to and from the center.



In some of these home-based daycare centers, several mothers help take care of the group of children.

Some effort has been made to teach the local mothers who serve as day care providers an assortment of basic skills for working with disabled children. These skills range from providing play activities and early stimulation, to feeding techniques, potty training, and teaching various daily living skills. But for the most part, the training has been too brief, follow-up visits by skilled workers too few, and the children too many and too severely disabled. Despite these limitations, most of the caregivers were doing a fairly good job. What impressed me most was the concern and affection they had for the children—even for those who were least attractive, least responsive, or the biggest trouble.

The Story of Frances

The APD Branch Center in Worcester has recruited a number of mothers of disabled children from poor communities to work as therapeutic assistants with multiply disabled children. I was deeply impressed by the way one of these mothers—an ebullient woman named Frances—worked with these children, demonstrating a wonderful combination of skill, patience, and love. What was most apparent was Frances’ great joy in working and playing with these children, and her gentle but skillful ways of bringing out the best in them.



Frances (center) in the Worcester APD Rehab Center

At the close of the day at the Worcester Center, we (Lara, a coordinating social worker, our chauffeur, and I) had a chance to drive Frances home. When we arrived at her home in a low-income settlement, I found she and her extended family of 10 people all lived crammed into a minute cement-block house consisting of one

room about 3 meters long and 2 ½ meters wide.

There was room for one double bed with a small mattress on the floor beside it. Curled up on the bed in a fetal position was Frances’ profoundly disabled child, who looked to be 5 years old but who was actually 20. The kitchen was crowded into one corner. There was virtually no furniture—partly because there was no room for it. On a small table was the family’s single luxury: a large color television set.



Frances explained that the biggest difficulty with her housing situation was that there was no toilet. As with in Clyde and Jacky’s household, everyone had to take turns using a plastic bucket, with no privacy. But the real problem was where to empty the full bucket. Neighbors sometimes let them empty it in their toilets, but needless to say they were less than enthusiastic.

The cost of installing a simple flush toilet at Frances’ house would not have been great. The plastic tubes for drainage into the sewage system were already installed to one side of the house. All that would be needed was a toilet bowl and a small enclosure for privacy. But Frances explained that as the single reliable breadwinner for the family she never was able to save enough to make even that modest investment.

What astounded me even more after seeing the conditions in which Frances lived was the way that every day she was able to show up to work at the APD Center immaculately dressed, energetic, and cheerful. I found it very humbling.

Fortunately, our visit to Frances’ home together with leaders in the APD program

paid off. Appalled by the conditions in which one of the programs most dedicated workers lived, the social worker accompanying us managed to obtain a toilet bowl and a few planks to build a small enclosed latrine. So now at least Frances’ family has a toilet.

Such experiences make it obvious why home visits are important!

Why television? We made a point of inviting Frances to the CBR workshop in Worcester, and her perspective was enlightening. For example, in one of our “But why?” and chain of causes sessions, the question came up, “Why do so many very poor family choose to buy a television rather than spending their very limited money on more basic or health-protecting essentials?” In this context, someone asked Frances why she had invested in a TV but not a toilet. Frances replied that the TV—apart from giving people whose lives were so walled-in a chance to see the larger world—was a means of maintaining a degree of sanity in a crowded, frustrating, oppressive environment filled with hardships and seemingly irresolvable problems. “For us, television is a kind of safety valve,” she said. “It helps us create an imaginary distance from our problems - when there isn’t really any distance at all.”

“You mean it acts like a kind of drug?” asked a psychologist. “A tranquilizer.”

“A painkiller,” answered Frances.

The Need for Simple Technological Creativity

In many of the Community Based Rehabilitation (CBR) programs I have visited in various countries, a common weakness is that, in a well-reasoned attempt to place more emphasis on the social aspects of rehabilitation, too little emphasis is placed on the technical and therapeutic side. Specifically, too often there is a shortage of individualized problem-solving creativity when it comes to technical aids and simple assistive devices.

When I was first invited as a consultant with the WC-APD, I suggested including a workshop that focused on this issue, but

The APD branch facilities



Laundry Service

Each of the WC-APD district branches we visited, in Cape Town, Worcester and George, had at least one large, comprehensive center with a wide spectrum of services and activities ranging from special education, to skills training programs, to “protected workshops,” to orthopedic appliance shops and “Roll In Shops” where families could purchase everything from assistive devices to diapers.

The quality of services in these large facilities tended to be much more sophisticated, professional, and in some ways better than in the neighborhood crèches. Again, what impressed me was the good will and caring attitude of many of the staff.



Making a baby's coffin in APD Worcester's protected workshop



Low cost wooden coffins and crosses help poor families spend less on deaths from AIDS.



A few of the staff members and trainers were themselves disabled, or were parents of disabled children. We talked about the importance of working more people with disabilities into leadership positions. The staff agreed and said they were trying to do more in this direction.

I was told that in South Africa the government supplied a full range of the necessary assistive devices, and that this was not an issue. However, as I visited homes and programs prior to the workshops, I found the same situation in the Western Cape that occurs in so many other places: namely that a lot of the wheelchairs, special seating arrangements, and other assistive devices routinely given to disabled children are inappropriate to their needs, and at times even counter-productive.

The Madiba Buggy

One brand of assistive equipment unique to South Africa is produced by a company called Shonaquip. This company was started



by a mother who began by designing a special stroller, or “buggy” for her daughter with cerebral palsy. The company evolved into a large, very profitable industry, and today is the main supplier of assistive equipment supplied by the government. The primary assistive device produced by Shonaquip is an elaborate stroller, the “Madiba buggy.” It is an ingenious, highly adaptable device with an assortment of felt-covered Velcro-adjustable cushions and wedges, which can be fitted to the needs of the individual child. But the buggy has two big problems: 1) it is very expensive; the government could respond to the needs of many more children by providing simpler, community-made, low cost equipment. And 2) the buggies are so massive that they are very hard to transport, especially on buses.



Thozama's Buggy Blues

An example of this transport problem was encountered by Thozama, the mother of a beautiful little boy with cerebral palsy. Thozama is a part time community rehabilitation worker in a new pilot program of the WC-APD called “Partners for Life.”

We visited her in her small wooden hut on a hillside in a poor settlement near Cape Town. It was pouring rain at the time we got to Thozama's house, and we got our van stuck in the mud. Her boyfriend and neighbors helped us push the van out.



When we asked Thozama about her needs, the first thing she mentioned was the trouble she had transporting her child. The Madiba buggy she had been given was way too big to get onto the crowded bus. And it didn't fold. She preferred a small foldable stroller she had.

But the stroller, too, had problems. When the boy's spastic body stiffened into extension, he would thrust forward in the seat so far that his feet would get entangled in the front wheels. She had tried all kinds of straps, including a groin strap that encircled his hips. But still he would thrust forward until his discomfort caused him to whimper plaintively.

Together we looked for a solution. We saw that a big part of the problem was that the back of the stroller slanted backwards, while the seat was horizontal. Even a non-spastic child would easily slide off. We

found that by lifting the front of the seat cushion higher, so the seat was at a right angle to the back, this prevented the boy from slipping forward. It also bent his hips more, which reduced his spasticity.

To keep the front of the seat cushion elevated, we used a roll of paper towel. This we held in place by running a piece of broomstick through a hole, so that the ends of the stick were held in place by the diagonal rods that formed the lateral forward edges of the stroller. That way the "seat lift" could be easily removed to fold the stroller for travel on the bus.



Thozama was thrilled at the discovery of such a simple, cost-free solution to a problem that had made her daily travel with her son so difficult. But what excited her most was the innovative problem-solving process. As a community rehab worker who regularly visited other mothers with disabled children, she now felt empowered to help them figure out simple, low cost



solutions. To some extent, the problem-solving process had been demystified.

Regularly, on our visits to homes and centers, we encountered similar, fairly simple technical problems. With a bit of imagination and ingenuity, many of these problems could have been quickly and easily resolved at little or no cost.



THE THREE WORKSHOPS

During my Western Cape visit I facilitated 3 two-day workshops in different districts. At first there were only a small number of people with disabilities and family members present, but by the third workshop almost half of the participants were people with disabilities or their parents. Participants covered a wide range of different disabilities, including cerebral palsy, spinal cord injury, blindness, epilepsy, and intellectual disability.

The first day of the assembly in each district was essentially a **seminar**. Using digital slide shows, I shared with the group a range of experiences from Mexico (notably PROJIMO) and other countries.

I stressed the importance of combining the best of CBR, which reaches out to those who are most marginalized, with the best of the Independent Living Movement, which involves empowerment and leadership by people with disabilities themselves. We dis-

cussed the importance of achieving a balance between the social and technical sides of rehabilitation.



We considered how essential it is to look at the most basic needs of the disabled person and their family, such as nutrition, health, housing, income generation, and not just at the disability. And above all, we shared examples and stories that demonstrate how empowering it can be to *look at people's strengths rather than their weaknesses*.

The second day was an interactive workshop. Participants repeatedly divided into small groups to identify and examine some of the biggest challenges facing people with disabilities and their families in South Africa today. We explored everything from short-term ways of coping at the individual and family level, to possible long-term solutions to the causes underlying the problems that those with disabilities encounter. With regard to the underlying causes, it was clear that collective action at the community, national, and even international level is needed. We did all this through discussions, debates, flipcharts, drawings, and role-plays.

Most importantly, we gave ample opportunity for the participants with disabilities, along with their parents and family members, to take the floor and tell their stories. We asked them to tell us about their hopes and dreams. What were the biggest obstacles they confronted in getting ahead with their lives? Which of the APD services they had experienced did they feel most positive about? What would they like to see done differently?

This in-depth interchange between the APD staff and their “clients” was an eye-opener for all of us. Many felt that, in terms of attitude change, it was the most important part of the workshops. In our pre-workshop planning sessions with the APD staff, it had been apparent

that, although there was a lot of charitable good will toward the people with disabilities and their families, too often there was a rather condescending attitude. Time and again I heard the professionals say that their clients lacked initiative, that all they wanted were handouts, and that they had no motivation to improve their lives. These pejorative judgments tended to be sweeping—to include “people with disability and their parents” categorically—as if all shared the same characteristics of dependency and lack of motivation.



Disabled participants tell their stories.

To interpret these characteristics of the clients as being the outcome of “internalized oppression” contained a kernel of truth, and seemed sympathetic. Yet I began to wonder if this diagnosis did not in itself inflate and perpetuate the problem. Too often the social workers expectation of apathy and lack of motivation of their “clients” seemed to produce a demeaning situation where they found what they were looking for.

But when the disabled people were included in the planning process, this “no hope” image was shattered. As the people with disabilities told their stories, it became clear they were very eager to overcome their difficulties and do something meaningful with their lives.

In summarizing what she had learned from the workshops, one of the staff said: “I think we need to look at people with disabilities and their families more as friends and partners in the search for solutions, and not as clients.”

ROLE-PLAYS

The role-plays, or improvised skits, performed during the APD workshops provided an opportunity to portray the uphill struggles and enormous barriers that people with disabilities and their families face. We divided into small groups, each of which prepared a role play, and then the groups took turns presenting to the plenary.

In the skits, the groups were asked to act out one of the biggest problems faced by disabled people, complete with the various personal, environmental and social obstacles they had to struggle with. And finally, they were asked to portray some kind of action that was taken, or might be taken, to overcome the obstacles. In this way, the role-plays would explore the possibility of positive solutions.

Most of the groups acted out true stories from the lives of the disabled participants. The stories covered a range of problems, many of them showing how difficulties created by the disability itself interacted with underlying societal problems such as poverty, drug addiction, gangs, transportation problems, inadequate or inappropriate services, lack of jobs, poor housing, and institutional bureaucracy. The following are several examples.

“MENU FOR SUCCESS”



#1. This skit opens in a restaurant where a blind woman (the role is acted by a woman who is actually blind) and a visually impaired woman are sitting at a table trying to read the menu—but can't.





#2. The blind woman points to her eyes, and asks the waitress for the food list in Braille. The waitress, not understanding, says "Bralen?"—which in Afrikaans means "spectacles" or "glasses." (Laughter).



#3. The guests try to explain. Finally the confused waitress goes to bring the manager.



#4. The discussion with the manager starts out with frustration and misunderstanding on both sides. But then an understanding is reached. The blind woman agrees to translate the menu into Braille. The manager agrees to make the Braille menu available to clients on request.



#5. Delighted at the management's goodwill, the two visually disabled guests agree to send their blind and disabled friends to the restaurant.

It's a win-win situation for all!

"NO DOORS OPEN"

Before describing this skit, I'd like to explain a bit about 2 of the actors—one a boy, the other a middle-aged man—whose homes I visited in the days before the workshop.

Archie is a bright 12-year-old boy. At the age of six he was jumping up and down on his mother's bed, when he fell and landed on the floor and broke his back.



David Werner and a social worker visit Archie in his home.

Archie lives with his mother and siblings in a well-kept cement-block house on the outskirts of the city of George. Despite his disability, Archie goes to school every day, where he is doing well. He dreams of studying to become a doctor.

Ebrahim is a middle-aged man who lives with his wife in a tiny, sheet-metal shack in a poor neighborhood of George, not far from Archie. Ebrahim is paraplegic from an accident in his youth. He has two wheelchairs, one manual and one electric, both donated by the government. It seems odd

to see an expensive electric chair sitting outside their primitive shack—but such



Ebrahim and his wife live in this small sheet metal shack.

contradictions are typical in South Africa. Although his resources are limited, Ebrahim says he is happy. He has a quiet, philosophic dignity and takes pride in being (relatively) self-sufficient. Like many of the so-called "Colored" people, Ebrahim is a devout Muslim, and therefore doesn't drink or use drugs. He is a gifted artist, somewhat in the style of Grandma Moses, and he sells his paintings for a living. He also makes ingenious rooftop antennae for houses. I was so impressed by one of his paintings, a colorful butterfly, that he gave it to me. In thanks, I have since sent him a set of prints of my own bird paintings.

Ebrahim and Archie both participate in the local APD center. Ebrahim has taken his fellow youthful wheelchair rider under his wing. He is a great role model for the boy, in many ways.

The skit that Archie and Ebrahim took part in presents the true story of an APD social worker and a mistreated child for whom she tried to find a new home. The story does not have a very happy ending because, in the real life situation it is based on, satisfactory living arrangements for the child portrayed in the skit have yet to be found.



#1. The skit opens with an APD social worker receiving a phone call about an intellectually disabled teenage girl who is being mistreated by her father. The father beats her and ties her up.



#2. The social worker visits the home. The disabled girl begs her to take her away from her cruel father. (The role of the father is played by Ebrahim, the paraplegic artist.)



3. The father is glad to see her go.



#4. The rest of the skit is the long story of the social worker's attempt to find some hostel, children's home, child care program, orphanage, protection agency or other program that will receive her.



#5. Finding no place for the girl, in desperation, the social worker tries to have her hospitalized. The chief doctor (played by Archie) is sympathetic, but can't take her.



#6. The doctor makes phone calls to try to find a place for the girl, but with no luck.



#7. The social worker calls the police to see if they can temporarily keep the child in jail.



#8. But when she takes the girl to the police station, the police chief (played by a young man with both legs amputated) sees them coming, and disappears out a side door, rather than deal with the issue.



#9. At last a woman in a senior rest home agrees to take the girl for a couple of months. Troubles quickly result. The girl—hungry for food and affection—gobbles down the snacks meant for everyone. But at least a temporary place for her has been found.



#10. At the end of the skit, the social worker explains that she is still looking for a better, long term, home care situation for the girl on which this skit was based.

This skit led to a long discussion of child neglect, overworked care-providers, and the inadequacy of existing programs to meet the overwhelming needs. Among the suggestions was that of starting a peer-counseling group among disabled youth.

“APPLYING FOR A JOB AT WAL-MART”

South Africa's new Constitution requires large companies to employ a small percentage of disabled persons and to not discriminate against persons with disability. But in practice, these ideals are often not realized. This skit is the true story of an intelligent, highly motivated young man named Novellin, who is quadriplegic. Although he is well educated, he has difficulties in finding work.



#1. The scene opens with Novellin applying for a clerical job at Wal-Mart. He is at a meeting with the board of job admissions.



#2. Although Novellin has the level of education, experience, and computer skills needed for the job, and he offers to demonstrate his capacity to do the work, the board members find one pretext after another for not giving him the job.



#3. Novellin realizes that only when disabled people organize and demand their constitutional rights, will they begin to achieve the opportunities they deserve.

(In his real life Novellin is an organizer and activist struggling for the rights of disabled persons.)

This skit led to a discussion of strategies for achieving more equal opportunities, and the need for associations like APD to play a stronger role in organizing and advocating for and with people with disabilities, to make sure the laws protecting their interests are applied. The suggestion was made that APD work more closely with other organizations of disabled persons.

CONCLUSIONS

At the close of the last workshop, when we met in an evaluation session with the leaders and organizers of the Association for Persons with Disability, it was agreed that one of the most valuable aspects of the workshops was that we had included disabled persons and family members as partners and peers in the problem solving process. It was agreed that in the future, people with disabilities, and parents of disabled children, should play a much stronger and more central role in the APD—not only because they would be good peer counselors and role models, but because their perspectives and experience was an invaluable resource for professionals and non-disabled staff.

“We need to be more inclusive ourselves,” concluded the Director of the Association.

Everyone also agreed that the problem of socioeconomic apartheid in South Africa—the huge gap between the rich and the poor, the powerful and the powerless—underlies and aggravates the inability of the vast majority of disabled people to meet their needs. For this reason the struggle for the rights and opportunities of people with disabilities needs to be seen as part of the larger struggle



for the rights and opportunities of the downtrodden, impoverished, and still oppressed majority, in Africa and worldwide.

PERSONAL REFLECTIONS

My visit to South Africa was both inspiring and disturbing. It was disturbing to see the persisting cruel gap between rich and poor—profound poverty side by side with enormous wealth. Although racial apartheid has officially ended, an economic apartheid still prevails, and the hope of the oppressed for a fairer distribution of resources and opportunities remains a still distant dream.



At the same time there is much that is inspiring in South Africa. Despite the hardships and injustices which the majority endure, I found in most of the people I encountered an uncrushable dignity. The spirit and vitality of people like Archie, and Ebrahim and Frances warm my heart when I think about them, and make my own tribulations seem small. There are so many barriers and challenges in their lives, and yet their eyes sparkle, and they remain caring and kind.

One of the deepest impressions made on me was that of a blind man and his family, whom we visited near George. He lives in a small hut with few amenities. And yet there is something regal about both him and his wife: a quiet pride and resolute independence.



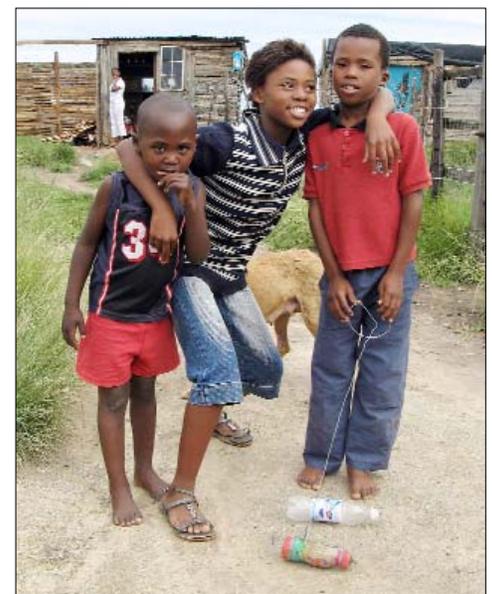
They earn their living by buying and selling chickens.

The children of the couple were full life and energy. They made toy cars out of old plastic pop bottles and pieces of wire. What life has in store for them, who knows? But for all the difficulties they face, they find joy in what they have and who they are.

They could teach us a lot.

NOTE: A longer version of this report, with more role plays and a third section on evaluation is available on our web site at:

www.healthwrights.org/dwpapers.htm.



HEALTHWRIGHTS

Workgroup for People's Health and Rights

Tel: (650) 325-7500 Fax: (650) 325-1080 email: info@healthwrights.org

NONPROFIT ORG.
U.S. POSTAGE
PAID
Palo Alto, CA
Permit No. 419

P.O. Box 1344
Palo Alto CA 94302
USA

Please visit our World Wide Web site at:
www.healthwrights.org
Also visit our Politics of Health
Knowledge Network: www.politicsofhealth.org

RETURN SERVICE
REQUESTED



Newsletter from the Sierra Madre #59

October 2007

HealthWrights

Board of Directors

Trude Bock
Roberto Fajardo
Barry Goldensohn
Bruce Hobson
Jim Hunter
Donald Laub
Eve Malo
Myra Polinger
Leopoldo Ribota
David Werner
Jason Weston
Efrain Zamora

International Advisory Board

Allison Akana – United States
Dwight Clark – Volunteers in Asia
David Sanders – South Africa
Mira Shiva – India
Michael Tan – Philippines
María Zúniga – Nicaragua

IMPORTANT: Because of sharp increases in mailing costs—and to reduce resource use—from now on our Newsletter will be primarily an Internet publication. We will notify you by email as each issue is posted to the web, so you can download it. Previous issues can be found at: www.healthwrights.org/newsletters.htm.

To receive email notification, please send a request to newsletter@healthwrights.org.

A small number of printed Newsletters will be available to those who cannot download it. If you require a printed copy, please notify us by email, or send your request to our post office box at the top of this page.

Your subscription payment helps us to continue sending the Newsletter to persons and groups in poor countries who lack Internet access.

If we do not hear from you at all, we will, reluctantly, remove you from our mailing list. We look forward to hearing from you.

Thank you!

CONTENTS

Page

South Africa's Uphill Battle for Equity and Health: Workshops facilitated with the Western Cape Association for Persons with Disability . . .	1
Factors Aggravating Disability	2
Internalized Oppression and Fetal Alcohol Syndrome	3
Visits to Daycare and Rehab Centers	4
The Story of Frances	5
The Need for Simple Technological Creativity	5
ADP Branch Facilities	6
The Three Workshops	7
Role Plays	8
Conclusions and Reflections	11

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

David Werner — Writing and Photos
Jim Hunter — Editing
Jason Weston — Editing, Design and Layout
Trude Bock — Proofreading

"The Earth is not dying. It is being killed, and the people killing it have names and addresses."

— Utah Phillips
Labor Organizer and Folk Singer