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

David Werner
HealthWrights
964 Hamilton Ave.
Palo Alto, CA, 94301, USA

healthwrights@igc.org
www.healthwrights.org
For three weeks in February and March 2002 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, after some years of negotiating, 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.

PART I: TWO WORLDS 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 is 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 for the needs of all its citizens tolerably well.

The new, socially progressive Constitution of South Africa includes many policies and statues to protect the rights of the disadvantaged, including guarantees of health care, education, adequate housing, water and sanitation, employment opportunities, and a fair minimal 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.

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 supply 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 the 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.

Government-built cement house are interspersed among the shacks.

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 all contribute to poverty. In low-income settlements and rural areas of the Western Cape nearly 60% of households have only one parent, mostly often a widowed or single mother. And 15% of households have no adult at all, only children. Adding to the extent of poverty, both through incapacitating illness and the death of breadwinners, is the high incidence of HIV-AIDS.

South Africa has one of the highest rates of HIV-AIDS in the world. It is estimated that over 20% of the population is HIV+. The incidence of HIV-AIDS varies greatly in different ethnic groups. For the purpose of health statistics, researchers still divide the population into the same 3 major racial groups, as did the ruling class during apartheid. These three groups—which have more to do with skin color than ethnic roots—are 1) "Whites," 2) "Blacks" (indigenous Africans), 3. "Colored" (people of mixed race, as well as those from India, Malaysia and China). The highest incidence of HIV+ is found among Blacks: around 25%. The lowest incidence of HIV+ is found among Whites: around 1%. In the "Colored population," the incidence of HIV+ is around 7%. This relative prevalence of AIDS largely correlates in reverse to the socioeconomic status of these 3 groups: Whites on the top, Blacks on the bottom, and "Colored" in the middle. This very strong correlation between social class and AIDS merits further study as to its exact causes. What is clear is that the problems of equity and poverty must be addressed if we are serious about improving the health of the people in the world.

The high incidence of HIV in South Africa has raised some important questions about the health benefits of breast-feeding. Some health authorities discourage breast-feeding. However, for impoverished families, the nutritional and immunologic benefits of breast-feeding are so great that even with HIV+ mothers, benefits may well outweigh the risks. Studies have shown that the risk of contracting HIV from their mothers' milk is lowest in babies who are exclusively breastfed.

One well known hallmark of AIDS is extreme weight loss. Indeed, a popular term for AIDS in South Africa is "Slim Disease." Being HIV+ is a highly stigmatized condition, and for this reason many women make an effort to look plump, and by implication, free of AIDS. Thus one of the rather odd health consequences of the AIDS epidemic is that it is contributing to a higher incidence of obesity, with escalating rates of chronic diseases such as heart disease, stroke, and diabetes.

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 microcephalous (small brains) and "intellectual disability." The more severely impaired brother, Morne, lives with Clyde, Jacky, and their two young children in tiny shack made of wood slats and tarpaper.

Clyde built this makeshift shack in a small space beside his father's relatively large cement-block house, which was constructed as part of the government housing program.

Morne, one of 2 brothers with intellectual impairment.
Clyde's cement-block house

Clyde's shack next to his father's cement-block house

Morne's less severely impaired brother, Eric, stays with the father, as do a half-sister of the 3 brothers, his 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 the 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 angry cruelty 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 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 have liked to work, too. But caring for Morne was a full time occupation—and there were no daycare 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 escorted him back home. But Morne has the mind of a toddler. Jacky was afraid he might be hit by a car, or be molested or given drugs by the local gangs. So she resigned herself to staying home and caring for Morne.

Both Jacky and Clyde were very kind to Morne, and did what they could to help him learn skills and become more self-reliant. They even taught him to help with household cores, 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 had 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 is 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, Worchester, and George.

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.

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

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.

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

Some of the most dedicated care providers at the APD centers are local mothers of disabled children.
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 a mother could park her disabled child while she worked.

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.

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 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 APD branch facilities

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.

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 work more in this direction.
The Story of Frances

The APD Branch Center in Worchester 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—a rotund, ebullient women 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.

At the close of the day at the Worchester 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 2½ 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 her 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 Worchester, 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 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 prof-
itable 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. 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 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 his 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 towels. 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 best of the Independent Living Movement, which involves empowerment and leadership by people with disabilities themselves. We discussed 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 levels, 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 levels 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 was 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.

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.

Disabled participants tell their stories.

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."
PART II: 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.

Cape Town Workshop Role-play: "GOOD INTENTIONS ARE NOT ENOUGH"

#1. The skit opens with a mother, worried about her daughter who suddenly falls ill with a severe headache.

#2. The terrified girl says she is losing her vision—but at first the mother doesn't believe her.

#3. A social worker from APD arrive and offers assistance, but the mother refuses help.

#4. The girl loses her sight completely. (The actress puts a paper napkin under her glasses so she really can't see).

#5. The Health Minister arrives, with an assistant, and proudly announces he is "donating a wheelchair for the disabled child."

#6. The mother explains that her girl is visually, not physically disabled. The Health Minister scolds her for being ungrateful.

#7. The Health Minister insists that the girl use the wheelchair. "You shouldn't look a gift horse in the mouth."

#8 The social worker from the APD returns, bringing with her a blind woman who walks with the help of a cane.

#9. The blind woman befriends the blind girl, helps her overcome her fear, and teaches her how to navigate with a cane.
In the plenary discussion that followed this skit, people gave numerous examples of inappropriate or useless aids and services they had been given—and the difficulties they often encountered in getting the service providers to take into account what they had to say—as if the professionals knew it all and their "clients" knew nothing.

People also emphasized the importance of peer counseling: disabled persons with more experience giving a hand and encouraging those with less. Good role models can make a big difference.

Cape Town Workshop Role-play: "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 ask 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 manger 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!

George Workshop Role-play: "KICKING THE HABIT—A DISABLED GANGTER'S TRUE STORY"

This next skit is the life story of one of the disabled workshop participants, named Patrick, who for years had been a thief to support his drug habit. In the first half of the skit, the role of Patrick is played by another former "gangster," Camphor, who became partially hemiplegic from a bullet wound in his head, but is still ambulatory. In the second part of the skit—after his accident—the role of Patrick is played by Patrick himself, now a wheelchair rider.
#1. The skit opens with Patrick, the young hoodlum (played by Camphor, with hat) secretly purchasing drugs from a street vendor (played by a man partially paralyzed by a stroke).

#2. High on drugs, Patrick returns home, where he fights with his family and his girlfriend. They try in vain to get him to give up drugs.

#3. A lay preacher talks to Patrick about correcting his ways. Patrick agrees to stop using drugs.

#4. But Patrick goes back to stealing, and buys more drugs from the street vendor.

#5. A social worker from the APD who is a friend of the family discovers Patrick buying drugs and tries to stop him. He hits her.

#6. A policeman intervenes.* Patrick and the policeman fight each other. The policeman uses karate.

#7. The policeman pins Patrick to the floor in a scissors grip.

#8. The policeman throws Patrick in jail (under a table).

#9. Patrick’s mother bails him out...

#10. ... and gives him the scolding of his life.

#11. Repentant, Patrick makes up with his girlfriend. He agrees to give up drugs and get a job.

* The policeman was played by Charles, a teenager with epilepsy who’s home we had visited in a low-income settlement a few days before. During the visit Charles, who reportedly was intellectually disabled, was very withdrawn and never spoke. I wasn’t sure whether he could. Yet there was something about him that made me suspect he was more intelligent than he seemed to be, and that he had been stigmatized and made to feel inferior because of his epileptic fits. To everyone’s surprise, in the skit Charles came to life, demonstrating agility and acting ability (as well as Karate ability) no one dreamed he had. When everyone applauded he blushed dark red, but beamed with pleasure.
I have some questions about the role of organized religion in human society, and may have had doubts about the role of divine intervention in this story. Even so, there is little question that for many people struggling to overcome drugs, alcohol, and other afflictions, "accepting God" appears to have given them the motivation to let go of their destructive habits and lead a more constructive life.

I have some questions about the role of organized religion in human society, and may have had doubts about the role of divine intervention in this story. Even so, there is little question that for many people struggling to overcome drugs, alcohol, and other afflictions, "accepting God" appears to have given them the motivation to let go of their destructive habits and lead a more constructive life.
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.

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 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 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 temporarily 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 organizations of disabled persons.
"THE TROUBLE WITH PUBLIC TRANSPORTATION"

#1. The skit opens with a young man in a wheelchair (acted by a young man who is paraplegic) trying to get on a bus (represented by rows of chairs with people sitting in them). The bus driver rudely refuses.

#2. The young man goes to the Dept. of Transit and registers a complaint. (The Transit Officer is played by the mother of a disabled child.)

#3. The Transit Officer summons the bus driver and explains to him that the new Constitution of South Africa requires that public transportation provide access to disabled persons. The driver protests that the bus is too crowded and there is no ramp. The Transit Office says, "You're a bright young fellow. I'm sure you can figure something out."

#4. The skit closes back on the street, with the disabled youth again flagging down the bus. This time the driver welcomes him, and the passengers help him to board and make room for him.

Everyone applauded the performance. But all admitted that to date many of the human rights and laws in the Constitution exist only on paper. It will be a long time before the skit's "ideal ending" commonly takes place in South Africa in real life.

"But if some of us get together and put on role-plays like this in the schools and in public meetings," suggested Patrick, the disabled former gangster, "I'll bet people's minds will begin to open, and things will begin to change!"

I presented some examples, using digital slides, of ways community theater, street theater, and puppet shows have been used in Mexico, Cuba, and elsewhere, as a strategy for awareness raising about social justice and human rights. We also discussed the role of the "Grey Eye Theater" in London, a highly skilled troupe of disabled persons. Through tragic-comedy and scathing satire, the Grey Eyes get people to appreciate the humanity of disabled persons, the need to break down barriers of prejudice, and the importance of giving everyone an equal chance to realize their potentials.

Conclusions

At the close of the last workshop we met in an evaluation session with the leaders and organizers of the Association for Persons with Disability. Most people felt 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 experiences are 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 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 Reflection

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, Ebrahim and Frances warms my heart when I think about them, and makes 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.
Evaluation of the Western Cape Association for Persons with Disability
Part III - Recommendations

Criteria for Evaluating Programs

A clear set of criteria is very helpful when one is evaluating the strengths and challenges of a program. Nine criteria that are relevant to evaluating programs for people with disabilities have been identified:

1. Comprehensiveness
   Is the program comprehensive? Is the quantity of services adequate? Does the program address the full range of the needs and possibilities of the person with disabilities as well as those of his or her family and community? Does it cover the whole life cycle? Does it include all those who might need the services? Does it emphasize services to those with the greatest needs?

2. Social Factors
   Does the program focus adequately on the social factors that contribute to or detract from the well being of the person with disabilities? Are family, friends and communities involved? Are the larger social and economic characteristics of the community within which the program operates given adequate consideration?

3. Technical Expertise
   Is the emphasis on the social aspects of the situation well balanced with a recognition of the importance of technical expertise?

4. Teaching
   Is there an adequate emphasis on teaching? Do highly trained people maximize their input by spending more time teaching others rather than providing direct service that others can be trained to do? Is there sufficient emphasis on independent living skills training? Do staff receive adequate and ongoing education and backup?

5. Inclusion
   Are the strengths and skills of people with disabilities utilized in the program and in relationship to other people with disabilities? Are efforts made to provide for the inclusion of people with disabilities in the larger community? In this regard, are both social and physical obstacles addressed?

6. Problem Solving Approach
   Does the program provide for a problem solving approach that includes the entire community of people who are impacted by the disability?

7. Self-Determination
   Does the program emphasize self-determination? In this regard, does it focus both on the physical obstacles to self determination, and the social factors that tend to undermine or enhance it? Does it promote appropriate educational and work opportunities?

8. Networking
   Does the program attempt to network with communities, other programs and governmental offices and facilities that may have an interest in, or an impact on, how people with disabilities are treated or benefited?

9. Self-esteem and Mutual Regard
   Does the program manifest and encourage a positive attitude both toward oneself and toward others in the program (staff as well as people with disabilities)? Are strengths rather than incapacities emphasized? This is not to suggest that people's limitations or needs for further training should be ignored, but an underlying attitude of care and affirmation energizes everyone for the challenges they must face.

*****

David Werner's Observations and Suggestions
Based on visit to Cape Town, Worcester, and George
Feb 24 - March 12, 2007

COMPREHENSIVENESS

Strong points:
- Comprehensive Services designed to meet the needs of disabled persons and their families.
- Strong emphasis on children.
- Attempt to reach those in greatest need—both in terms of type of disability (intellectual) and in location (poorest urban settlements and rural areas).
- The commitment of the "Partners for Life" initiative to identify and meet the needs of disabled children as early as possible and continue assistance as the children grow up and become adults.

Challenges:
- Hit or miss process of identifying the children/persons/families in greatest need, with little idea of how many needy persons fall between the cracks.
- Too heavy a "case load" for virtually all the professionals, resulting in inadequate instruction and assistance of those working in branches and centers.
- Insufficient home visits, together with insufficient involvement and teaching of mothers and family members.
• The most obvious solution to attending the needs of many more disabled persons is through Community Based Rehabilitation, whereby "consumers" at the community level (disabled persons, family members, and others including even schoolchildren) gradually become "providers" of basic rehabilitation services.

• Schoolchildren might be enlisted to conduct house-to-house surveys—similar to the "participatory epidemiology" surveys that were conducted by schoolchildren in Mexico to identify and assist the children under 5 years old who were undernourished (a process portrayed in the CBR Workshops).

SOCIAL FACTORS

Strong points:
• Strong emphasis on the social aspects of disability.
• The efforts of "Partners for Life" to seek help from disabled persons and their families in identifying and assisting other persons in need.
• Response to the greatest needs of families—i.e. day care for children of working mothers.

Challenges:
• While there have been increasing efforts to recruit disabled persons and mothers as rehab assistants, community outreach workers, and peer counselors, a great deal more needs to be done in this area.
• One problem staff members are well aware of—and need to further explore—are ways to deal with the overwhelming burden of poverty, which is made even more difficult due to inadequate housing, high unemployment, low wages, and the enormous problems with transportation. Staff members spoke of the deep sense of hopelessness that many disabled persons and their families experience, and the feeling of impotence and internalized oppression—in part a remnant from the apartheid era.

• To help people overcome this sense of internalized oppression—and the apathy, social dysfunction, alcohol and drug use, crime and violence that results from it—a lot more study and training needs to take place among those involved with the APD (including staff, disabled person, family members, and others). These studies should include ways to help people gain confidence in themselves, their strengths, and their abilities to collectively improve their situations.

• Perhaps the biggest unanswered problem is the vast number of disabled persons, especially children, who remain unidentified and unreached, especially in rural areas. How to respond to this situation is indeed a daunting challenge. Care must be exerted in this regard that in conducting surveys to identify the unmet needs, unrealistic expectations not be generated with regard to capacity of the system to meet all the needs that might be identified.

TECHNICAL FACTORS

Challenges:
• Especially at the level of day-care centers and homes, there is much more emphasis on the social than the therapeutic side of rehab. This is partly because there are so few OTs and PTs (far too few to meet the enormous needs), and partly because some of the therapists need more practical, hands-on apprenticeship and experience in innovative problem-solving where resources are limited.

TEACHING

Strong points:
• Good, well-rounded care and training of disabled children in (some of) the special care facilities.
• Training of disabled persons in work skills, and efforts to arrange employment.

Challenges:
• The role of the professionals involved in the APD must shift more from providers to that of "multipliers." The professionals must learn to use virtually every occasion of service provision as an opportunity to teach others the most basic knowledge and skills, in a clear, simplified, and adequate way. Most important of all, they must learn to take—and teach—an innovative problem-solving approach, adapting their rehabilitation measures to the limitations and possibilities of each child and each situation. (Without this, the process is likely to turn into ineffective routine that falls far short of helping disabled persons reach their potential.)

• Highly variable level of competence of "care-givers" in the different day care centers. While in some cases this is excellent, in others the centers function as little more than holding stations for disabled children while their mothers work.

INCLUSION

Strong points:
• Measures to mainstream children who have potential for learning in regular schools, combined with special schooling and "stimulation" centers for those who are more profoundly disabled.

• Staff members also recognized that while they have spent a great deal of time capacitating mothers in the homes, and occasionally fathers, they have not given adequate attention to the possibilities of involving bothers and sisters. They see this as a possibility with real potential—as well as a way to somewhat relieve the burden on the mother, as well as building family cohesion.

• In the Worchester area and elsewhere, disabled persons and family members are being recruited to identify the disabled children in their neighborhoods.
Advancement toward including disabled persons and family members (mostly mothers as rehab assistants and peer counselors, both in the centers and communities).

**Challenges:**
- The possibilities of children helping children, in the home, in the day-care centers, in the special education environment, and in schools needs to further explored and developed. Many participants were quite excited by the Child-to-Child activities I presented in the seminars, and are eager to introduce them in their work. Some staff members have already been encouraging more able disabled children to assist others, and gave some excellent examples (such as one child helping to feed another). But now they are motivated to do this much more.

**PROBLEM SOLVING APPROACH**

**Strong points:**
- I was impressed by eagerness of the participants in the seminars and the workshops to increase their abilities, to discuss their challenges, and seek ways to serve to help disabled persons and their families in a more effective and empowering way. Their openness to discussing problems and looking for solutions—even to the very daunting obstacles in the South African situation—is a big step forward toward finding solutions, or at least more effective ways of helping people cope.

**Challenges:**
- A greater use could be made of role-plays and "sociodramas" exploring difficulties, obstacles, and ways of overcoming them, could be quite useful. Many of the workshop participants were excited by the possibilities of such role-plays for "situation-al analysis" among staff, disabled persons, and families, and for awareness raising activities in communities, school, and the work place.

**SELF DETERMINATION**

**Strong points:**
- The focus on helping disabled persons and their families to become self-determined and more self-sufficient is to be commended. At the same time this is balanced with efforts to help disabled persons and their families get their allotted financial aid, as well as the services and assistive equipment they are entitled to.

**NETWORKING**

**Strong points:**
- Efforts to collaborate and interact with other services and programs, especially those of the government (e.g. Dept. of Health and Dept. of Education). While this process of working together and sharing responsibilities still has a long way to go, APD is making an effort to work together with the different sectors, and to find ways to overcome the bureaucratic obstacles to dealing with some of the government agencies.
- Decentralized administration with independent branches in many areas.

**SELF-ESTEEM AND MUTUAL SELF REGARD**

**Strong points:**
- I was impressed by the caring and commitment of many of the APD staff at all levels. I was also quite moved by the insight and sensitivity of the groups organizing the role-plays in the workshops, notably the way they succeeded in casting the disabled participants in ways that inspired them to play an outstanding, active role. (For example the way in which, in the George workshop, Charles—a shy epileptic, moderately intellectually disabled teenager—was given a role of a policeman arresting a drug addict, where he could demonstrate his quite remarkable karate skills without having to speak a word: making him the star of the skit.

**Challenges**
- At times some of the staff referred to disabled persons categorically as unmotivated, resigned to remaining dependent, and reluctant to become self-determined. This may be true for many disabled persons in the Western Cape—but certainly not for all! Indeed, one of the most eye-opening aspects of the CBR workshops was the eagerness of most of the disabled participants to overcome obstacles, become self-sufficient, and make something of their lives. This interchange of disabled persons—and family members—with the APD staff in a free and equal exchange of ideas was perhaps one of the most valuable aspects of the workshops. Staff became aware of the enormous potential of such self-determined and motivated disabled persons as role models for other disabled persons and families, and as front-line rehab extension workers at the community level.