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The Role of Disabled Persons in Overcoming Rural Poverty in Andhra Pradesh, India

Enabling the “poorest of the poor”

In February/March, 2002, I (David Werner) was invited to India as a consultant to a comprehensive program to reduce poverty throughout the rural area of Andhra Pradesh. Aware that many large-scale, top-down programs to combat poverty have failed to reach the most destitute and marginalized persons—and consequently have left them more–the designers of the Andhra Pradesh Rural Poverty Reduction Program are taking a different approach. The focus will be on the most needy and vulnerable groups in rural areas (where 2/3 of the state’s 76 million population live).

These "most vulnerable" groups include:

* the “poorest of the poor,” including the jobless and homeless
* those belonging to the lowest "untouchable" caste (Dalits)
* tribal and nomadic populations
* women (especially widows and single mothers)
* children (especially girls)
* the indigent elderly and infirm
* disabled persons.

Following the principles of participation and empowerment, the plan is for representatives from all of these most vulnerable groups to play a leading role in the development and implementation of the poverty reduction strategy. This may sound like common sense. But in a land where class, caste, and gender hierarchies are so deeply entrenched, achieving effective leadership and a more equal voice for those who have been on the bottom of the pecking order for millennia will be a complex challenge.

The Andhra Pradesh Rural Poverty Reduction Program (APRPRP) is under the state government’s overall coordination, but is being facilitated by “Commitments,” a branch of a very capable Indian NGO called the Society for Elimination of Poverty (SERC). Although the Bank would have preferred a more mainstream advisor, Commitments insisted that I (David Werner) be the "independent consultant" to the disability component of the APRPRP. One reason they wanted me was that the self-help books, Disabled Village Children and Nothing About Us Without Us are so widely used in community programs in India.

While in India, I met with several groups that have translated or are translating these books into Telugu, the area’s traditional language. (One result of my visit was to engender more cooperation between the diverse programs working in this field.) Also I found that the Telugu version of Where There Is No Doctor is widely used. And what I saw reinforced for me the importance of understanding and working with the diverse programs that are run by and for disabled villagers.

This issue takes us to the state of Andhra Pradesh, India, where early this year David Werner went as a consultant for a statewide Rural Poverty Reduction Program. Although the consultancy concerned the needs of disabled persons, it turned out that the lack of adequate health care at the village of poverty was a substantial contributing cause of poverty. The possibility arose for self-help groups of disabled villagers to play a central role in meeting the health needs of the whole community.

Also, as an insert within this Newsletter, we provide an update on our new Politics of Health Knowledge Network, a joint project of HealthWrights and the International People’s Health Council. See: www.politicsofhealth.org
The Disability Component of the Andhra Pradesh Rural Poverty Reduction Program has many features of Community Based Rehabilitation (CBR). However it also has an essential quality of the Independent Living Movement, in that it tries to open the way for leadership by disabled persons themselves.

Disabled persons played a leading role, even sang the planning stage of the program, by conducting the initial survey for an "In-Depth Analysis of the Disability Issues" in the state. To oversee the survey, SERC chose the Regional Office of "Action Aid," an NGO based in the state capital, Hyderabad. Action Aid has a long history of working for the rights and opportunities of marginalized groups, especially disabled persons.

To plan the survey, Action Aid met with disabled activists in Hyderabad, as well as from the rural area. Together they designed a creative, culturally appropriate strategy for conducting the in-depth survey. The result was a remarkably sensitive, participatory process with some unique features.

**Avoiding the typical problems with surveys.** Surveys in which outsiders question people in poor communities have in recent years drawn a lot of criticism. Because they treat the interviewers or feel humiliated by their questions, too often those interviewed give false or misleading information. Or they Confuse with the interviewers what they want to know. When interviewers are pushy, condescending, or insensitive to the socio-cultural dynamics of the community, data is even more likely to be invalid.

The communications problems common to surveys were minimized in the Andhra Pradesh disability survey in 3 ways:

1. The information gatherers were themselves disabled, giving them insight and making them peers of those primarily being interviewed.
2. The information gatherers were specially trained in cross-cultural sensitivity, methods of empowerment and community participation.
3. The survey was conducted in a dynamic process of group building, community awareness raising and collective action.

**Recruitment of Interviewers.** To recruit the information gatherers, Action Aid carefully screened scores of young, literate, disabled persons, from which they picked a group of 80. In the selection, interviewers, and a humble background were given more weight than academic qualifications. On purpose, the group included persons with a wide range of disabilities. It also included representatives from more vulnerable groups, especially persons of rural origins, women, those from lower classes, including Dalits (untouchables), and persons from religious minorities (Muslims, Christians).

**Coverage of the Survey: The study covered 52 villages from 20 mandals (groups of villages) in 15 districts. Locations were selected based on those with the biggest problems and needs. These included:**

- interior rural areas (those with the poorest, most deprived and underserved populations)
- homelands of "primitive" tribal groups or "schedule caste" populations (Uttouchables, Dalits)
- the driest (unirrigated) least fertile lands
- areas with shortage of drinking water, especially those with high fluoride content (a cause of widespread disability-fluorosis)
- areas with high unemployment or a large population of peasants who are landless or have very small holdings
- areas with very low literacy rates

In the survey, all of these factors (and many others) were evaluated in terms of their impact on incidence of disability and influence on disabled persons' well-being.

To survey a village (usually with 1000 to 2000 persons), the information gatherers would stay in the village for 5 days, living in the homes of persons with different disabilities. Whenever possible, the team would stay in the home of the most severely disabled or marginalized person or family in the village (paying the costs). They would do their best to become a friend of the disabled person, the family, and neighbors, trying to gain insight into their spectrum of problems, while helping to resolve or look for ways of resolving the ones they could.

**Community approach:** The study was designed around "a rights-based approach to Community Based Rehabilitation (CBR)" - proactively addressed the following areas:

- Rescue planning and protection for the destitute among the disabled persons
- Protection of the rights of the "disabled"
- Education
- Medical integration - care, aids and appliances
- Social reintegration
- Work and income generating opportunities.

But the information gatherers did far more than collect data. They brought disabled people together to discuss their mutual problems and needs. They helped groups of disabled persons begin to form self-help groups, or "sangams." They conducted awareness raising activities, including public theater, in the villages surveyed. And before leaving the village they organized a kind of "disability pride" march of disabled people and their families.

**WANTED: Village health care**

In the villages the lack of adequate health services is a huge problem, especially for disabled people and the "poorest of the poor." In theory, Primary Health Care in India is a universal human right. In practice, hundreds of millions of people face enormous obstacles to getting the health care they need.

In India government health services exist on three levels. At the village level are the "angamandals" or trained workers, mostly village girls with a couple of weeks training. Their skills and responsibilities are so limited that they have little credibility among the villagers. They weigh babies, fill out forms, and help rally people for immunization. However, they are taught almost no curative skills. They know little about useful medicines (most of which they are forbidden to use) than do local shop keepers or the traditional healers. They refer the sick or injured to the closest District Health Center.

But District Health Centers (the second level of service) are few and far between. Time and cost to get there, and the series of bribes or "tips" required to get service, are such that the poor often go untreated. Or, worse, they use unqualified others who are not trained to the needs of disabled people. As a result, the hungry children become even less resistant to the "diseases of poverty." Thus "health care" becomes another cause of ill health, disability, and death. Health workers do their best to become a friend of the disabled person, the family, and neighbors, trying to gain insight into their spectrum of problems, while helping to resolve or look for ways of resolving the ones they could.

This approach could also help bring about a cultural revolution that would do their best to become a friend of the disabled person, the family, and neighbors, trying to gain insight into their spectrum of problems, while helping to resolve or look for ways of resolving the ones they could.

**A possible solution:** Displaced persons as health workers, backed by their sangams.

In our discussions with villagers, SERC, and the APRPRP planners, an exciting possibility arose. Why not train selected members of the disability sangams as village health workers? The step would be a part...

**Enabling work with disabled children is also taking their health needs at low cost can be an important step toward reducing poverty. In the long run it can save more money than it costs (for people and government alike).**
This village boy with cerebral palsy, who used to fear "Playground for All" pictures in Nothing About Us Without Us. Ram (boy on right) and another boy were fascinated by the One of the biggest benefits of schooling "Child-to-Child" Integrating Disabled Kids through with other children, he scowled silently for a moment. Then with a big grin he nodded, Yes! would like to help build such a playground with other children, he scowled silently for a moment. When the Sangam leader asked Ram if he would like to help build such a playground with other children, he scowled silently for a moment. Then with a big grin he nodded, Yes! Integrating Disabled Kids through "Child-to-Child" One of the biggest benefits of schooling potentially is not always met — and it is here that "Child-to-Child" can make a difference. Whether in school or out of school, it can help a group of children reach out, include, and assist "the child who is different." The Child-to-Child methodology started in the International Year of the Child (1979) and is now practiced in over 70 countries. It began with the idea of teaching school-aged children to help meet the health and development needs of their baby brothers and sisters. (For example, the importance of giving lots of fluid to an infant with diarrhea.) But Child-to-Child has evolved. Now it includes activities and games to sensitize children to relate in a friendly and enabling ways to children with special needs. (Our books Disabled Village Children and Nothing About Us Without Us both have sections on Child-to-Child disability-related activities. Both books are available in full on our web site (www.healthwrights.org). In Gundal, Hakeempet, and other sangams, whenever we discussed Child-to-Child, there was a lot of interest, especially among the adults, in the disabled children in the Aruna Sangam played a central role. Leadership by the children themselves is a key to success of Child-to-Child. Possibility of disability sangams in managing Community Based Rehabilitation On our visits to the sangams, we encountered a strong felt need for Community Based Rehabilitation (CBR). Currently families have to travel far and spend lots for even the most basic rehabilitation services or assistive devices. To make things worse, private doctors and traditional healers often exploit poor families by prescribing medicines or herbal remedies for mental retardation, cerebral palsy, and other disabilities that require developmental rather than curative measures. (See photos, page 4) Members of various disability sangams were eager to start a CBR program in their village. In our discussions, the idea arose that one or two sangam members could be trained as CBR workers, and the rest of the sangam could assist them. The necessary training and back-up, and referrals could be arranged by Commitments, SERC and the government. The children’s contributions would be used as a CBR center. Already the disabled youngsters in the Aruna Sangam, on their own initiative, were moving in this direction. The leadership of Commitments and SERC was already thinking along similar lines. Disability sangams could become involved in CBR activities, first in selected villages where interest and potential were high. They might begin with informal peer counseling. (For example, a mother with years of experience assisting her disabled child could advise and assist less experienced mothers.) CBR training could be conceptual. Through short workshops, trainees (chosen for their interest, ability and compassion) could be taught basic skills. Through hands-on apprenticeship, they could learn physical rehabilitation. They could employ Child-to-Child activities to help special needs children gain entry into schools. They could lead activities to promote community understanding and opportunities. And they could organize prevention campaigns. Development of CBR activities at the village level is one of the program goals. However, in the Mahabubnagar project, rehabilitation services are still largely provided to professionals. While a good back-up and referral system is essential for effective CBR, much more needs to be done to train local CBR workers at the village level. And if these CBR workers are disabled persons, their commitment, empathy and quality of work is likely to be better. In some of the disability sangams, such as in Gundal, there are bright young disabled persons who would jump at the chance to become village CBR workers, and would likely do an excellent job. Some might go on to become leaders for human rights in their respective communities. Their contribution would help win appreciation and respect for disabled persons in general. (For examples of how this empowering process has evolved in Mexico and elsewhere, see the books, Disabled Village Children and Nothing About Us Without Us.) A complaint about many surveys in and of disadvantaged communities is that they build up people’s expectations, but the promised benefits never arrive. People feel used, deceived, and stop cooperating. To avoid this, in Andhra Pradesh the survey included a service component. It brought disabled people and their families together to discuss their needs, learn their legal entitlements, and begin to take organized action. At the same time, it launched a constructive dialogue with the larger community and with village authorities to help open the way for more equal opportunities and more accountability. It also helped the disabled persons gain free access to medical and orthopedic facilities. Good role models. In many ways, the employment and leadership of disabled persons as key agents in the Andhra Pradesh analytic survey was a ground breaking approach. The fact that the facilitators were themselves disabled provided excellent role models for the disabled villagers and their families. The methodology deserves dissemination. Fortunately, it is well documented, and much of the community process was video-taped. An important resource.

Meeting with the information gatherers. Before the disabled “information gatherers” began to visit the villages, they went through an intensive, highly participatory learning process using methods of group dynamics, confidence building, peer counseling, and “strategies of empowerment.” The sessions involved role plays in which everyone practiced listening to and learning from one another as equals. These methods - drawing on the “pedagogy of liberation” of Paulo Freire - were designed to help them reach out to multiple disabled persons, build their self-esteem, and win their trust, so that those interviewed could gain the self-confidence and trust to speak openly of their true feelings, needs, obstacles, fears, and hopes. In my meeting with the information gatherers at Action Aid, we started by introducing ourselves and describing the difficulties and challenges we had experienced as disabled persons, from early childhood on, as well as the circumsptions and even disabilities that had changed our lives for the better. Many of the group had grown up in extreme poverty. Nevertheless, I realized that this group was exceptional, in that all of them had somehow succeeded in finding decent work, gaining self-esteem, and playing a dignified, productive role in society. The information gatherers described the pervasive social and economic obstacles they had struggled to overcome. For example, one village girl, who belonged to the Dalti (untouchable) caste, described herself as being “triple disabled.” She was: 1) disabled (one paralyzed by polio), 2) female, and 3) a Dalit, i.e. born in the “low-est,” most denigrated social caste. Added to all this, she had grown up in a situation of rural poverty. Tellingly, she said that the hardship and social stigma she had suffered for being Dalit was greater than that of being disabled. This comment made clear the importance of looking at disability within the entire sociocultural and economic context. As I listened to the different members of the study team describe their personal backgrounds and difficulties, I was impressed by how far they had come in terms of coping skills and personal esteem. It was apparent that their being involved in the DPGI survey analysis - designed to give a voice to rural poor disabled persons - has been an eye-opening and empowering process not only for the disabled persons interviewed, but also for these information gatherers themselves. A true win-win situation. Most of the disabled information gatherers had not known each other before they were recruited. But in less than a year they had developed a strong sense of camaraderie and solidarity. More than most disabled persons (where the pecking order between different disabilities can be as unkind as that in society as a whole), they reached out to include one another as equals. For example, those who had learned sign language (to interview deaf persons) enthusiastically translated our full discussion into sign, both have sections on Child-to-Child disability-related activities. Both books are available in full on our web site (www.healthwrights.org). As I listened to the different members of the study team describe their personal backgrounds and difficulties, I was impressed by how far they had come in terms of coping skills and personal esteem. It was apparent that their being involved in the DPGI survey analysis - designed to give a voice to rural poor disabled persons - has been an eye-opening and empowering process not only for the disabled persons interviewed, but also for these information gatherers themselves. A true win-win situation. Most of the disabled information gatherers had not known each other before they were recruit- ed. But in less than a year they had developed a strong sense of camaraderie and solidarity. More than most disabled persons (where the pecking order between different disabilities can be as unkind as that in society as a whole), they reached out to include one another as equals. For example, those who had learned sign lan- guage (to interview deaf persons) enthusiasm- ially translated our full discussion into sign, for the 2 participants who were deaf.

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"Sangams" (Self-Help Groups) as an entry point to poverty reduction

As a pilot project of the APRPRP, a Community Based Disability Intervention has been introduced in Mahabubnagar District, one of the poorest in Andhra Pradesh. Since 1984 the Committees team has been working in Mahabubnagar, in community development, poverty reduction, and disability rights. The goal is to empower vulnerable groups by "building participatory and self-managed institutions and developing sustainable livelihood capacities."

One of the APRPRP approaches to poverty reduction is through the formation and assistance of "sangams" (common interest self-help groups) among the most disadvantaged groups (women, Dalits, landless peasants, disabled persons, etc.) at the village level. Through the sangam, people can work together to improve their situation, both socially and economically. They can define their common needs and biggest barriers, and collectively take problem-solving action including income-generating activities.

"Visits to "Disability Sangams"

The program staff (who love acronyms) refer to the Vikalangula Sangams as DCIGs: short for Disability-oriented Common Interest Groups. In smaller villages there is often a single Disability Sangam with 15 to 20 members. At meetings, disabled children and mentally handicapped persons are usually accompanied by their parents. However, if the sangam discovers, some of the older children play important leadership roles themselves.

In the Disability Sangams we visited, members made a conscious effort to reach out and include all disabled persons in the village, whatever their disability or social status. In terms of breaking down entrenched barriers, this was a big step forward. Because of their common identity as "disabled persons," sangam members are more willing to reach out to others across the traditional walls of class, caste, gender, and even generation (adults to children). Persons who otherwise have never spoken to each other - and certainly not on an equal level - were beginning to do so. And by doing so, they discover the other things they had in common, apart from disability. In terms of transcending entrenched social barriers, the sangams are real bridge builders.

Neighborhood Houses. Many Disability Sangams were eager to start their own "neighborhood house." They envisioned this as a place where disabled people could meet and exchange ideas, organize activities, master new skills, assist one another with therapy, and learn from visiting rehabilitation professionals. Most important, they saw the Neighborhood House as a place where disabled people can play a visible, pro-active role in the community.

Some of the sangams have applied to Committees for financial help in setting up a neighborhood house. Two groups were so eager that they have already acquired donated land, even before Committees had responded to their request.

"Déjà vu - PROJIMO makes it to India"

Visits to "Disability Sangams"

In 1999, in the small village of Kogui, Committees opened a modest Project Office, which doubles as a community rehabilitation and training center. In 6 mandals, the team has helped to start 70 "Vikalangula Sangams" (self-help groups of disabled persons). To help organize and facilitate the initiative, Committees has trained several "Community Coordinators" (CCs), as well as 20 village activists and social workers, mostly disabled. I was impressed by the dedication and ability of this group. The fact that 3/4 of them are disabled contributes to their understanding of key issues and commitment to empowerment of other disabled persons.

Open-Air Theater to Raise Awareness

In this, Committees is to be applauded. In other programs, such leadership by disabled persons is less common. In the (relative few) Community Based Rehabilitation (CBR) programs in India, seldom do disabled persons play leading roles in program implementation. If this Committees model of having programs for disabled persons staffed by disabled persons is successfully scaled up within the statewide APRPRP program - as is the plan - it will be a breakthrough of far-reaching significance.

"Sangams" (Self-Help Groups)

In the Disability Sangams we visited, members said that one of their biggest accomplishments so far has been their campaign to treat with respect. Awareness-raising activities, including educational street theatre, have reportedly had an impact on changing how people see disability.

"Visits to "Disability Sangams""

"Now people don't call us 'the lame boy' or 'the blind girl' but address us by our real names," children said proudly.

Reaching across barriers.

Open-Air Theater to Raise Awareness

As we approached the Neighborhood House, there was a sudden feeling of déjà vu. In front of the old building, and inside, the young adults built a variety of rustic playground and rehabilitation equipment. These included parallel bars made from bamboo poles and forked sticks, a simple press-boarded eart for easy access, a swing made with an old car tire, a large barrel padded with foam rubber for physical therapy, and an arm-exercise device made with a wheelchair wheel mounted on a wall. All looked disconcertingly familiar.

"Where did you get the idea to make all this local, low-cost equipment?" I asked.

"From a book somebody gave us called Villaged Children on the Margins of the disabled youths. When the head of Committees told him I was the author of the book (actually titled Disabled Village Children), his jaw fell open with surprise. From that moment on the whole group welcomed me like an old friend.

"Exploring Alternatives to School"

The next day we visited the Sudha Chandran Vikalanga Sangam in Hakempet village. Here the dynamics were quite different. Most of the children in the sangam were developmentally delayed. Suggested explanations for this high incidence of mental retardation ranged from consanguineous marriages (inbreeding), to pesticides or other chemical contaminants, to the prevalence of premature birth due to the high rates of malnutrition and anemia of pregnant women. (In rural India rates of anemia in women of child-bearing age run as high as 90%).

In our discussion, it became clear that many of these mentally slow children suffered from harsh rejection and exclusion, some times even within their own families.

"For example, one 11-year-old mildly retarded girl at the meeting was very withdrawn and morose (and very thin). Since her mother had died 3 years before, she lived with her father, who was also mentally a bit slow. He brought her to the sangam meetings only because the group urged him to do so. The girl could talk, but her father would not let her speak for herself. He said he had not sent her to school or sought any kind of help for her because she was "totally useless."

Other parents had better reasons for not sending their slow children. Teachers often gave their physically slow children, they said, schooling was cruel. Mothers said they had tried to get their children into the local primary school, but with frightening results. Even when the children were accepted, teachers had little patience with them. They scolded or humiliated them in front of the other children, who learned similar behavior from their teachers.

At the Sangam meeting there was an angry looking mildly retarded 13 year old boy named Ram, who sat on the floor all hunched into a ball, scowling. Ram's mother said she had tried several times to place him in school. But after a few days he had always run away. Now the boy flatly refused to go, even when she threatened to beat him.

"Visits to "Disability Sangams""

"Fighting for entitlements."

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"Visits to "Disability Sangams""

Our first visit was to the Aruna Vikalangula Sangam in Guindal village. The Sangam President is a 16-year-old schoolboy who has one leg withered by polio. Most of the sangam's members are, in fact, school-aged children. The rest are adults of every age, with diverse disabilities, mostly physical.

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Visits to "Disability Sangams"

The program staff (who love acronyms) refer to the Vikalangula Sangams as DCIGs: short for Disability-oriented Common Interest Groups. In smaller villages there is often a single Disability Sangam with 15 to 20 members. At meetings, disabled children and mentally handicapped persons are usually accompanied by their parents. However, I need to add that I discovered, some of the older children play important leadership roles themselves.

Reaching across barriers. In the Disability Sangams we visited, members had a conscious effort to reach out and include all disabled persons in the village, whatever their disability or social status. In terms of breaking down entrenched barriers, this was a big step forward. Because of their common identity as "disabled persons," sangam members are more willing to reach out to others across the traditional walls of class, caste, gender, and even generation (adults to children). Persons who otherwise have never spoken to each other - and certainly not on an equal level - were beginning to do so. And by doing so, they discover the other things they had in common, apart from disability. In terms of transcending entrenched social barriers, the sangams are real bridge builders.

Fighting for entitlements. What impressed me most on visiting the sangams was people's energy and enthusiasm in trying to collectively improve their personal situations. Groups have been making an organized demand for their legal certification and entitlements (which have proved an uphill battle). They have worked to get disabled children into schools (which is their legal right, but not easy). And with the help of Commitments, they are striving to get necessary medical care, surgery, and assistive devices they need.

Winning respect in the community. In all the Disability Sangams we visited, members said that one of their biggest accomplishments so far has been their campaign to treat with respect. Awareness-raising activities, including educational outreach, have reportedly had an impact on changing how people see disability.

"Now people don't call us 'the lame boy' or the 'blind girl' but address us by our real names," children said proudly.

When I heard this, from my own childhood I recalled how important "names" can be. In our discussion, it became clear that many of these mentally slow children suffered from harsh rejection and exclusion, sometimes even within their own families. In terms of transcending entrenched social barriers, the sangams are real bridge builders.

"Vikalangula Sangams"

In 1999, in the small village of Kogii, Commitments opened a modest Project Office, which doubles as a community rehabilitation and training center. In 6 mandals, the team has helped to start 70 "Vikalangula Sangams" (self-help groups of disabled persons). To help organize and facilitate the initiative, Commitments has trained several "Community Coordinators" (CCs), as well as 20 village activists and social workers, mostly disabled. I was impressed by the dedication and ability of this group. The fact that 3/4 of them are disabled contributes to their understanding of key issues and commitment to empowerment of other disabled persons.

In this, Commitments is to be applauded. In other programs, such leadership by disabled persons is less than common. Even in the (relatively few) Community Based Rehabilitation (CBR) programs in India, seldom do disabled persons play leading roles in program implementation. If this Commitments model of having programs for disabled persons staffed by disabled persons is successfully scaled up within the statewide APRPRP program – as is the plan – it will be a breakthrough of far-reaching significance.

"Sangams" (Self-Help Groups)

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"Where did you get the ideas to make all this local, low-cost equipment?" I asked.

"From a book somebody gave us called Village Disabled Children," answered one of the disabled youths. When the head of Commitments told him I was the author of the book (actually titled Disabled Village Children), his jaw fell open with surprise. From that moment on the whole group welcomed me like an old friend.

"Déjà vu - PROJIMO makes it to India"

Our first visit was to the Aruna Vikalangula Sangam in Guv达尔 Village. The Sangam President is a 16-year-old schoolboy who has one leg withered by polio. Most of the sangam's members are, in fact, school-aged children. The rest are adults of every age, with diverse disabilities, mostly physical.

The young Gandula group told us excitedly about their new "Community Rehabilitation House," an old building they obtained from the local panchayat (community council) and are creatively adapting. They were obviously proud of it and were eager to take us there. Our visit coordinator said we were pressed for time, but I begged to see the house, and he agreed.

As we approached the Neighborhood House, I had a sudden feeling of déjà vu. In front of the old building, and inside, the youths had built a variety of rustic playground and rehabilitation equipment. These included parallel bars made from bamboo poles and forked sticks, a simple pressed-earth ramp for easy access, a swing made with an old car tire, a large barrel padded with foam rubber for physical therapy, and an arm-exercise device made with a wheelchair wheel mounted on a wall. All looked disarmingly familiar.

"Visits to "Disability Sangams""

"Sangams" use village theater to raise awareness about disability rights. Too often, both doctors and healers abuse and exploit disabled persons. Here a village doctor refuses to treat a blind man who was bitten by a deadly snake. "If he dies, so what" says the doctor. "He's of no use anyway!"

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Meeting with the information gatherers.

Before the disabled information gatherers began to visit the villages, they went through an intensive, highly participatory learning process using methods of group dynamics, confidence building, peer counseling, and "strategies of empowerment." The sessions involved role plays in which everyone practiced listening and learning to understand from one another as equals. These methods - drawing on the "pedagogy of liberation" of Paulo Freire - were designed to help them reach out to multiple disabled persons, build their self-esteem, and win their trust, so that those interviewed could gain the confidence and trust to speak openly of their true feelings, needs, obstacles, fears, and hopes. In my meeting with the information gatherers at Action Aid, we started by introducing ourselves and describing the difficulties and challenges we had experienced as disabled persons, from early childhood on, as well as the circumstances and events that had changed our lives for the better. Many of the group had grown up in extreme poverty. Nevertheless, I realized that this group was exceptional, in that all of them had somehow succeeded in finding decent work, gaining self-esteem, and playing a dignified, productive role in society.

The information gatherers described the pervasive social and economic obstacles they had struggled to overcome. For example, one village girl, who belonged to the Dalit (untouchable) caste, described herself as being "triple disabled." She was: 1) disabled (one paralyzed by polio), 2) female, and 3) a Dalit, i.e. born into the "lowest," most denigrated social caste. Added to all this, she had grown up in a situation of rural poverty. Tellingly, she said that the hardship and social stigma she had suffered for being Dalit was greater than that of being disabled. This comment made clear the importance of looking at disability within the entire sociocultural and economic context. As I listened to the different members of the study team describe their personal backgroungs and difficulties, I was impressed by how far they had come in terms of coping skills and personal esteem. It was apparent that being involved in the DPIG survey/analysis - designed to give a voice to rural poor disabled persons - has been an eye-opening and empowering process not only for the disabled persons interviewed, but also for these information gatherers themselves. A true win-win situation.

Most of the disabled information gatherers had not known each other before they were recruited. But in less than a year they had developed a strong sense of camaraderie and solidarity. More than most disabled persons (where the pecking order between different disabilities can be as simplistic as that in society as a whole), they reached out to include another as equals. For example, those who had learned sign language (to interview deaf persons) enthusiastically translated our full discussion into sign, for the 2 participants who were deaf.

One of the biggest benefits of schooling potentially is that it gets children in a community working and playing together, as companions and even as equals. But this would like to help build such a playground with other children, he scowled silently for a moment. Then with a big grin he nodded, Yes!

Possibility of disability sangams in managing Community Based Rehabilitation

On our visits to the sangams, we encountered a strong felt need for Community Based Rehabilitation (CBR). Currently families have to travel far and spend lots of even the most basic rehabilitation services or assistive devices. To make things worse, private doctors and traditional healers often exploit poor families by prescribing medicines or herbal remedies for mental retardation, cerebral palsy, and other disabilities that require developmental rather than curative measures. (See photos, page 4)

In some of the disability sangams, such as in Gundual, there are bright young disabled persons who would jump at the chance to become village CBR workers, and would likely do an excellent job. Some might go on to become leaders for human rights in their communities. Their contribution would help win appreciation and respect for disabled persons in general. (For examples of how this empowering process has evolved in Mexico and elsewhere, see the books, Disabled Village Children and Nothing About Us Without Us.)
The Disability Component of the Andhra Pradesh Rural Poverty Reduction Program has many features of Community Based Rehabilitation (CBR). However, it also has an essential quality of the Independent Living Movement, in that it tries to open the way for leadership by disabled persons themselves. Dismissed persons played a leading role, even designing the planning stage of the program, by conducting the initial survey for an “In-Depth Analysis of the Disability Issues” in the state. In order to conduct the survey, SERC picked the Regional Office of “Action Aid,” an NGO based in the state capital, Hyderabad. Action Aid has a long history of working for the rights and opportunities of marginalized groups, especially disabled persons.

To plan the survey, Action Aid met with disabled activists in Hyderabad, as well as from the rural area. Together they designed a creative, culturally appropriate strategy for conducting the in-depth survey. The result was a remarkably sensitive, participatory process with some unique features.

Avoiding the typical problems with surveys.

Surveys in which outsiders question people in poor communities have in recent years drawn a lot of criticism. Because they distrust the interviewers or feel humiliated by their questions, too often these interviews give false or misleading information. Or they forget that it is the disabled who want to know. When interviewers are pushy, condescending, or insensitive to the socio-cultural dynamics of the community, data is even more likely to be biased.

The communications problems common to surveys were minimized in the Andhra Pradesh disability survey in 3 ways:

1. The information gatherers were themselves disabled, giving them insight and making them peers of those primarily being interviewed.
2. The information gatherers were specially trained in cross-cultural sensitivity, methods of empowerment of marginalized communities.
3. The survey was conducted with a dynamic process of group building, community awareness raising and collective action.

Recruitment of Interviewers. To recruit the information gatherers, Action Aid carefully screened scores of young, literate, disabled persons, from which they picked a group of 80. In the selection, interview priorities, and a humble background were given more weight than academic qualifications. On purpose, the group included persons with a wide range of disabilities. It also included representatives from more vulnerable groups, especially persons of rural origin, women, those from lower classes, including Dalits (untouchables), and persons from religious minorities (Muslims, Christians).

Coverage of the Survey: The study covered 52 villages from 20 mandals (groups of villages) in 15 districts. Locations were selected based on those with the greatest problems and needs. These included:

- interior rural areas (those with the poorest, most deprived and underserved populations)
- homelands of “primitive” tribal groups or “schedule caste” populations (Untouchables, Dalits)
- the diest (unirrigated) least fertile lands
- areas with shortage of drinking water, especially those with high fluoride content (a cause of widespread disability—fluorosis)
- areas with high unemployment or a large population of peasants who are landless or have very small holdings
- areas with very low literacy rates.

In the survey, all of these factors (and many others) were evaluated in terms of their impact on incidence of disability and influence to disabled persons’ well-being.

To survey a village (usually with 1000 to 2000 persons), the information gatherers would stay in the village for 5 days, living in the homes of persons with different disabilities. Whenever possible, the team members stayed in the homes of the most severely disabled or marginalized person or family in the village (paying the costs). They would do their best to become a friend of the disabled person, the family, and neighbors, trying to gain insight into their spectrum of problems, while helping to resolve or look for ways of resolving the ones they could.

WANTED: Village health care

In the villages the lack of adequate health services is a huge problem, especially for disabled persons and the poor. In theory, Primary Health Care in India is a universal human right. In practice, hundreds of millions of people face enormous obstacles to getting the health care they need.

In India government health services exist on several levels. At the village level are the “anganwadis.” These groups of trained women, mostly village girls with a couple of weeks training. Their skills and responsibilities are so limited that they have little credibility among the villagers. They weigh babies, fill out forms, and help rally people for immunization. However, they are taught almost no curative skills. They know little about useful medicines (most of which they are forbidden to use) than do local shopkeepers or the traditional healers. They refer the sick or injured to the closest District Health Centers.

But District Health Centers (the second level of service) are few and far between. Time and cost to get there, and the series of bribes or “tips” required to get service, are such that the poor often go untreated. Or worse, they use untrained home remedies and “worshippers” and, in the end, are even worse off than when they started.

A possible solution:

We visited self-help groups in villages in Mahabubnagar District of Andhra Pradesh, where ox carts are still the main form of transportation.

Potential for “scaling up”

Within the self-help disability sangams in Mahabubnagar, the interest and potential exist to improve health and rehabilitation services at the village level. Such an empowering approach could help meet an urgent need of the most vulnerable people. It would also increase respect and opportunities for disabled persons. And reduce poverty.

This community-based approach could be introduced, on trial basis, as part of the Andhra Pradesh Rural Poverty Reduction Program. The APRPRP, as a state-wide program, has the necessary links to govern and to the health, education, and other relevant ministries. If successful, the approach can be incrementally scaled up to include all 500 mandals under the coverage of the APRPRP.

Conclusion

Clearly, to substantially reduce poverty in India - or anywhere else - will require transformation of unjust socioeconomic and political structures that go far beyond village-based health and rehabilitation measures. But in the meantime, such measures can help the most vulnerable villagers cope a bit more successfully. By coming together to solve their problems, perhaps in time a critical mass of “people who care for one another as equals” will be reached so that, collectively, they can begin to demand and work for more far-reaching change.

In the planning stage of the program, by conducting the initial survey for an “In-Depth Analysis of the Disability Issues”...
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www.healthwrights.org
Also visit our new Politics of Health Knowledge Network: www.politicsofhealth.org

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This issue takes us to the state of Andhra Pradesh, India, where early this year David Werner went as a consultant for a statewide Rural Poverty Reduction Program. Although the consultancy concerned the needs of disabled persons, it turned out that the lack of adequate health care at the village of poverty was a substantial contributing cause of poverty. The possibility arose for self-help groups of disabled villagers to play a central role in meeting the health needs of the whole community.

Also, as an insert within this Newsletter, we provide an update on our new Politics of Health Knowledge Network, a joint project of HealthWrights and the International People’s Health Council. See: www.politicsofhealth.org

The Role of Disabled Persons in Overcoming Rural Poverty in Andhra Pradesh, India

Enabling the “poorest of the poor”

In February/March, 2002, I (David Werner) was invited to India as a consultant to a comprehensive program to reduce poverty throughout the rural area of Andhra Pradesh. Aware that many large-scale, top-down programs to combat poverty have failed to reach the most destitute and marginalized persons—and consequently have failed to generate the kind of development which reduces poverty—this project was created to enable the “poorest of the poor” to play a central role in poverty reduction. The plan is for representatives from all of these most vulnerable groups to play a leading role in the development and implementation of the poverty reduction strategy. This may sound like common sense. But in a land where class, caste, and gender hierarchies are so deeply entrenched, achieving effective leadership and a more equal voice for those who have been on the bottom of the pecking order for millennia will be a complex challenge.

The Andhra Pradesh Rural Poverty Reduction Program (APRPRP), piloted by Commitments, is under ordinance of the state government (whose capital is Hyderabad, in east-central India) and financed in large part by the World Bank. However, local non-government organizations (NGOs) are playing a leading role in both the program design and field work.

The disability component of the APRPRP is being facilitated by “Commitments,” a branch of a very capable Indian NGO called the Society for Elimination of Poverty (SERC). Although the Bank would have preferred a more mainstream advisor, Commitments insisted that I (David Werner) be the “independent consultant” to the disability component of the APRPRP. One reason they wanted me was that the self-help books, Disabled Village Children and Nothing About Us Without Us are so widely used in community programs in India.

While in India, I met with several groups that have translated or are translating these books into the local language. (One result of my visit was to engender more cooperation between the diverse programs working in this field.) Also I found that the Telugu version of Where There Is No Doctor is widely used. And what pleased me more, facilitators of both community based health and rehabilitation training programs are using discovery-based and learner-centered.

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