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***Strengthening the Role of Disabled People in
Community Based Rehabilitation Programmes***

David Werner

I write to you, not as a health worker or rehabilitation professional, but from the perspective of someone with a disability. This is because we disabled people - like other disadvantaged groups - need a louder voice in the discussions and decisions that affect us.

I cannot, of course, speak for all disabled people because - like *non-disabled* persons - each of us is unique. We come from different cultures, different socio-economic classes, different histories of oppression and/or opportunity. Also, we have different kinds and degrees of disability. This sometimes divides us or breeds misunderstanding, even among ourselves. Each of us perceives the world based on our own vision, experience, and bias.

Yet we disabled people - everywhere on Earth, I think - do have something unusual in common. We have been *judged*, and to a greater or lesser extent *defined*, by our impairments rather than by our abilities or potentials.

What we all have in common is our difference. Many of our strengths are the fruit of our weakness. Even the experience of being marginalised - pushed out, if you like, from the mainstream of humanity - gives us an unusual perspective on the human saga: an *outsider's insight* from the vantage point of the disadvantaged. Be it with a limp, a cane, a wheelchair, or simply an off-beat dream, we march to a different drummer. And surely, today's world sorely needs a breaking of the ranks and questioning of the *status quo*.

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Rehabilitation of the Person or Society

To look creatively for solutions, it is essential that we view disability within the context of the local community as well as within the fabric of humanity as a whole. The needs of disabled people are related to the world that surrounds them; the culture, the attitudes and beliefs of family and community, local economic constraints and resources. Too often professionals working with disabled persons forget this synergy of factors. They tend to approach disability out of context, as an individual deficiency; treating it as a purely medical or technological problem.

The official response to disability is to provide something called REHABILITATION. Some disabled activists dislike the term *rehabilitation*, viewing it as an attempt to normalize or re-form the disabled person to fit into the existing society, rather than to require society to appreciate and adapt to the differences of the disabled person. In the words of Joshua Malinga, a leader of Disabled Persons International in Zimbabwe, "*It is society that needs to be rehabilitated.*"

I appreciate this viewpoint. Nevertheless, I feel that for certain disabled persons, many of the activities and procedures known as *rehabilitation* can be important, especially if they help those persons to empower themselves, become more independent, and demand their rights.

But we must remember that disabled people - like other human beings - have certain vital needs, some of which clearly come before conventional *rehabilitation*. I am thinking of basic needs for *survival*.

In the rich countries of the North, activists in the *Independent Living Movement* have gained a lot of ground in their demands for *equal rights* and accessibility. But because these disabled activists mostly come from middle class backgrounds, they take certain things for granted. When they talk about *accessibility*, usually they mean such things as ramps, elevators and public transportation.

But for disabled people in the South - as for many non-disabled people - the main accessibility issues are how to access enough food, clean water, decent shelter and primary health care. Ramps and lifts for wheelchair accessibility are of low priority for persons who don't have a wheelchair - nor enough to eat.

In today's world - with its development strategies and structural adjustment policies that favour the rich at the expense of the disadvantaged - such basic needs are becoming more and more difficult to meet for all poor and marginalised people. This includes disabled people, most of whom are also poor and marginalised. It is therefore important that we disabled people do not look at either our

marginalisation or our need for rehabilitation - which I prefer to call *enablement* - as separate from the struggles for enablement of other marginalised groups.

Rehabilitation as Enablement

Given these considerations, we can then ask: *what kind of 'rehabilitation efforts' would be most appropriate from the perspective of disabled people?* Clearly they are ones which will help us to empower ourselves, so that we can join with other disadvantaged and socially concerned groups, both locally and globally, to work towards changing the power structures that deny us our basic rights to meet our needs and potentials.

So what kind of rehabilitation efforts now exist in developing countries? Current programmes embrace a wide spectrum, falling between two poles: *top down* and *bottom up*, or put another way, between those that try to *normalize* disabled people and those that help to *liberate* them.

Unfortunately, most services for disabled people remain very institutionalized and top-down. Delivered by costly professionals in hospitals or large urban centres, they reach only a tiny portion of those in need. Many of these palatial urban centres are equipped with all the most modern, expensive therapeutic equipment, imported from the North. Too often, however, much of the therapy executed on disabled clients tends to be at best ritualistic and at worst, counter-productive. Even special seating is often thoughtlessly standardized. Children of all sizes and disabilities are strapped into oversized chairs that increase, rather than help correct spasticity and deformity. In some of these institutions you get the feeling that disabled people are lovingly dehumanized, on the assembly line of an elaborate robotics factory.

Fortunately, during the last 10 or 15 years, things have begun to change. Forward-looking planners have begun to realize that the needs of the vast majority of disabled persons can only be met by *deinstitutionalising* services, so as to place rehabilitation skills in the people's hands. There has been a growing effort by national and international agencies - and by a few of the more socially conscious disabled people's organizations - to reach the countless disabled people whose needs and potentials remain unmet.

The most exciting and potentially revolutionary of these approaches - loosely dubbed ***community based rehabilitation*** or ***CBR*** - attempts to move the focus of rehabilitation from the extravagant "*rehabilitation palaces*" into under-served communities and homes.

Community Based Rehabilitation

In spite of the World Health Organization's early attempts to rigidly standardize the approach, the term *CBR* covers a wide range of initiatives. At one end of the spectrum are ***large CBR programmes launched by government***. Although these programmes do reach out to many more people, they still tend to be structured from the top down, in ways that *normalize* rather than *empower*. Rehabilitation measures usually follow a set of oversimplified, prepackaged lesson plans. In practice they tend to be even more ritualistic and ineffective than in the large urban rehabilitation centres. The whole approach is very hierarchical. The *district supervisor* supervises the *local supervisor* who supervises the *home supervisor* who supervises the *disabled person*, who is definitely the 'low man' on the totem pole. Thus disabled people become the objects, not the subjects, of their rehabilitation. They are trained to jump through hoops and are graded for their performance.

Of course, some good things do happen in these programmes, especially when there is creative leadership that dares to go outside the norms. This sometimes happens when disabled persons themselves take the reins and begin to restructure the programme on their terms.

At the opposite end of the CBR spectrum are ***small community programmes run by the disabled persons, or by families of disabled children***. These tend to be woefully disorganized yet very exciting. Every programme is different. In the best ones, disabled persons become peer counsellors and skilled technicians. They may make low-cost wheelchairs, orthopaedic appliances, prosthetics, and a wide range of rehabilitation aids. We have found that the quality of their work is often as good as or superior to that of many highly trained rehabilitation professionals; especially in the care they take in making sure appliances and therapy really match the needs and wishes of each individual.

This is not to say there is no role for rehabilitation professionals in these programmes. Even in Community Rehabilitation Programmes run and controlled by disabled persons, the co-operation of competent professionals for teaching and back-up is essential. Indeed, the lack of adequate professional support and referral is one of the biggest obstacles to successful community based rehabilitation.

In some of the most outstanding CBR programmes, a vital role in their success has been played by exceptional rehabilitation professionals - ones who are willing to go into the community, share their knowledge, and learn from the people *as equals*. But even more

important to the success is the *leadership of disabled persons themselves*. I want to emphasize, that when given the opportunity, ***disabled persons - even with limited formal education - often make excellent rehabilitation workers and community health workers***. We discovered this in Mexico, completely by accident. Let me tell you about it.

Project PROJIMO

For much of the last 27 years I have worked with villagers in Western Mexico. Together we have looked for solutions to health-related needs. A villager-run, primary health care programme, known as Project Piaxtla, gradually evolved. Villagers wishing to participate would choose someone from their community to take a 6 week training course as a *village health worker*.

In the selection of health workers, a curious thing happened. Some villages chose a disabled person. This was not because they thought a disabled person would make an especially good health worker, but rather because they were the persons most available. Unable to do hard physical farm work, and often unmarried because of local taboos, disabled persons were among the few persons with free time to take the training course.

As the years went by, some of these disabled health workers proved to be among the most outstanding. This is understandable, because by becoming health workers disabled villagers were able to move from a marginalised to a centrally important role in their community. Because of what they had been through themselves, they had more empathy for other disadvantaged persons and tended to reach out to those in greatest need. So in a way, through health work, their weaknesses led to their strengths.

In time, some of these disabled health workers became leaders in the village health programme. They became concerned that their programme did relatively little for disabled persons, especially children. So, in 1981, the health workers met with families in the village of Ajoya, and started a programme called PROJIMO: Programme of Rehabilitation Organised by Disabled Youth of Western Mexico.

PROJIMO is run and almost entirely staffed by disabled villagers. Although most have little or no formal schooling, they have achieved recognition for a wide range of skills. These include peer counselling, medical and nursing care as needed, physical and occupational therapy, as well as self-care and skills training. The team makes high

quality low-cost orthopaedic appliances, artificial limbs, wheelchairs and many other aids and equipment. Most of these skills they have learned through hands-on, problem-solving apprenticeship during short-term visits by friendly rehabilitation professionals, many of them disabled themselves.

The collective of disabled young people at PROJIMO, have begun to assert their rights as they have gained respect and self-confidence. They have pressured the local community to build ramps for access into public buildings and stores, and they have pushed for the admittance of disabled children into normal school.

One time the soldiers came into town and arrested a village health worker on charges of treating a fugitive whom they had shot. As the soldiers threw the health worker into their truck to take him away, the able-bodied villagers peeped from their doorways. But they dared not protest, for the soldiers can be quite brutal. However the disabled group from PROJIMO did not hesitate. On crutches and in wheelchairs, the young men and women surrounded the truck and refused to move until the soldiers released the health worker. Put off their guard, the soldiers gave in.

Although the modest centre is located in a small, remote village, disabled young people have come to it from 10 states of Mexico. The programme has gained the respect of the director of the government-run centre for Rehabilitation and Special Education (CREE) in the state capital. CREE has contracted with PROJIMO for prosthetics and orthopaedic appliances.

At present, the PROJIMO team of disabled villagers has a contract with UNICEF to make low-cost, high quality wheelchairs for disability programmes in other states.

The PROJIMO team has also functioned as advisors and facilitators in neighbouring states, where disabled persons themselves have been recruited to take the lead in setting up and managing CBR programmes. Today a growing network of non-government, community based programmes with strong leadership by disabled people and/or their families exists through Mexico and much of Central America.

For the last two years, PROJIMO has led a series of short courses for disabled leaders from different community programmes in Mexico and Central America, focusing on themes ranging from limb-making to massage therapy; from disability rights to sexuality of disabled persons, as well as integration into schools and peer counselling among disabled persons and among parents. These courses and workshops have expanded out of PROJIMO and are conducted by the larger, grassroots network of community programmes.

Although this network is made up completely of non-government

programmes, the disabled team members of PROJIMO have also willingly collaborated with government efforts. But they deeply value their freedom and the control of their own programme - so much so that they turned down an offer to work at the CREE centre in their own state for three times their present, very modest salaries.

Finding Solutions from My Own Disability

My conviction that disabled persons - including children - should be involved in the planning and decision-making of their own rehabilitation also comes from painful personal experience. I have an inherited, progressive muscular atrophy. As a child I had very weak feet and ankles, so an orthopaedist prescribed arch supports. I hated them because they made it harder for me to walk. They bent my weak ankles outwardly just enough so that I was constantly spraining my ankles. I would take them out of my shoes and hide them. But my parents would find out and both they and the orthopaedist would scold me.

Later I was prescribed heavy metal braces which, although they protected my ankles, made walking so awkward and tiring that I finally abandoned them.

It was not until many years later, when I began to work with the team of disabled villagers in PROJIMO, that I realised that as a child my disapproval of the arch supports made sense. They did me more harm than good.

Only since I began to work with PROJIMO, and could actually take part in the design and improvement of my own braces, do I now finally have top-quality orthopaedic appliances that really answer my needs. They are plastic AFOs but with unique features adapted specifically to my needs. With these braces I can walk better than I could 30 years ago, although without them I can barely walk. They have given me a new degree of freedom and ability.

For this reason I am committed to ensuring that other disabled persons participate as fully as possible in the assessment of their own needs and in the design, innovation, and evaluation of their own therapy and equipment.

Programmes Staffed by Disabled Persons

There are many reasons why a Community Based Rehabilitation Programme should be run and staffed mostly by local disabled

persons:

1. Having an impairment themselves, disabled workers tend to be ***more sensitive to the needs and feelings of other disabled persons***, and to relate to them more as equals.
2. Because of this sense of equality, disabled workers are more likely to ***involve those who come for rehabilitation in the problem solving process***. This permits the disabled person, even children, to play an important role in evaluating their own needs and in figuring out what therapy or assistive equipment might be effective. Disabled people then become the subjects, not the objects of rehabilitation.
3. Because of the insight which the workers gain from their own disability, the rehabilitation aids and therapy they provide often are ***better at meeting the real needs*** - and felt needs of the user. I should point out that in the United States and Europe, some of the real breakthroughs in design of wheelchairs, prosthetics, and orthopaedic appliances have been achieved by disabled wheelchair riders, amputees, and brace users who were dissatisfied with the equipment provided to them, and set out the improvements needed.
4. Perhaps most important of all, is the ***role model*** that disabled leaders and crafts-persons present to disabled children and their families. In Mexico, as in many parts of the world, most parents deeply love their disabled children. But they overprotect them. They do everything for them and don't let them do much for themselves. They may not let them play with other children, or go to school. They expect them to be helpless and dependent.

When such a family arrives at a place like PROJIMO these attitudes are turned around. They see villagers in wheelchairs and on crutches running the programme, providing medical and nursing care, performing a wide range of skilled services, earning their living, raising families, enjoying life and doing more to help other people than most non-disabled persons do. It gives both the parents and their child a whole new sense of what is possible. And that is the first big step of rehabilitation - or *enablement* - and ultimately of *empowerment*.
5. Having disabled persons with limited formal education as leaders and highly skilled technicians helps to ***demystify*** the rehabilitation process in two ways. Firstly, it shows that first

hand experience and personal commitment can sometimes outweigh years of rote learning and official diplomas. Secondly, it moves disabled persons - both providers and clients - from the role of passive recipients to ***active participants*** in the rehabilitation or enablement process. Thus the example that a competent disabled rehabilitation worker provides not only engenders a new, more open and liberating point of view to the disabled child and family, but also to society as a whole. This includes non-disabled rehabilitation professionals, whose attitudes are often the hardest to change.

6. Finally, providing hands-on skills training and leadership opportunities to disabled persons in the field of rehabilitation and disability rights provides ***employment*** of such people in an area where their disability can also be an outstanding qualification in community health work. I hope the day will soon come where planners and administrators recognise the positive side of disability and - other qualifications being equal - give preference to disabled candidates in job training and leadership roles, especially in relation to work with disabled people.

Disability Rights

I believe that disabled person have a right to play a leading role in organisations and activities that are committed to their well-being. In this context, we should compare *disability rights* with *women's rights*. Most of us would find it unconscionable today, that an organisation committed to the concerns of women should be directed and staffed by men. Yet when it comes to disability, our consciousness is still underdeveloped. In many countries organisations for "the disabled" - especially rehabilitation centres and programmes - are still mainly directed and staffed by non-disabled persons.

Women in most countries are now demanding their right to leadership in the institutions that represent their concerns. It is high time for disabled people everywhere to make similar demands. It is time for planners and administrators to provide the necessary opportunity, encouragement and appropriate skills training. And, most urgently of all, it is time for non-disabled professionals to recognise the right of disabled persons to self control, and therefore to gracefully step to one side, into a role where they, as professionals, are no longer *on top* but rather *on tap*.

Strengthening the Role of Disabled Persons

But much remains to be done. I list below a number of shifts in policies and approaches that decision makers, funding agencies, and organisations of disabled people might make to help strengthen the role and leadership of disabled persons in community based rehabilitation.

1. Organisations of disabled people and the families of disabled children: In order to achieve a democratic and potentially liberating restructuring of rehabilitation services, disabled people need to organise and pressure for full participation and leadership in all stages of the CBR process.

In the industrialised countries of the North, during the last 15 or 20 years disabled people have made substantial advances in terms of opportunities and more equal rights. But changes in legislation and public attitude have come about through a long struggle and organised demand by disabled people themselves. Today, in poorer countries in the South, disabled people are just beginning to organise. In Mauritania, under the leadership of Tambo Camara, such organisations have played a key role initiating CBR programmes with strong input by disabled persons. It is important that such bottom-up approaches be encouraged and supported.

2. Redefinition of goals: Our present rehabilitation efforts, while important, are but a drop in the bucket. The structural violence in today's world is producing disability much faster than it can be dealt with. The most basic needs of millions of disabled persons will not be met until the social forces that are increasing levels of poverty, malnutrition, unemployment, homelessness, repression, and violation of human rights, are confronted and transformed. Therefore, *the long term value of any rehabilitation or development effort must be evaluated in terms of how much it empowers marginalised groups and moves us towards fairer, more fully democratic social structures.*

It is important that disabled persons themselves contribute to rethinking the underlying goal of "rehabilitation". Too often the tacit objective of rehabilitation - especially when approached from the *top down* - is to **normalise** disabled persons into the existing unfair and discriminatory society. By contrast, the goal of the alternative, bottom-up approach is to **empower** disabled persons to joining in an organised struggle of all disadvantaged and marginalised groups, to *change our present society* into one that is fairer, more truly democratic, and more accepting of human differences.

The goal of this alternative approach to rehabilitation - or

enablement - is not to force open doors which society has closed against disabled persons. Rather it is to tear down the walls of inequality, to work towards a social order that provides all people - weak and strong, rich or poor, male or female, black, brown or white - with equal respect, equal opportunities, and equal rights.

3. Restructuring rehabilitation services from a *top-down* to a *bottom-up* approach: Too often so-called "community-based rehabilitation" is, in practice, more of an extension programme into poor communities than one that is based, planned, and managed within the community itself. The skills pyramid needs to be turned on its side so that disabled persons and family members become the front line workers, so that mid-level rehabilitation workers become facilitators and back-up persons rather than "supervisors" (which means those who *look down from above*) and the rehabilitation professionals are *on tap* and not *on top*.

When selecting rehabilitation workers (at all levels, but especially at the community level) *disability must be rated as a key qualification*. Give it equal or greater weight than other qualifications. Actively look for and encourage disabled candidates for such posts. Provide special or additional training for disabled persons in the areas where they may be weak or less qualified (including organisational and management skills).

4. Re-educating professionals: They need to recognise and contribute to the development of the full potential of disabled persons, to involve their disabled clients as partners in defining and resolving their needs, and to encourage their participation and leadership in the planning, administration, delivery and evaluation of rehabilitation services.

5. Encourage and support the active participation of organisations of disabled people in launching and leading CBR initiatives: Funding agencies and organisations should give *preferential funding* to CBR programmes which are started or run by disabled groups, or which maintain a certain quota of disabled people at all levels, including technical and decision-making posts. Be sure programmes include a plan and timetable for training disabled persons to move into such posts.

6. Set up small community centres: Here disabled persons and family members can come together, exchange information and

experiences, and provide assistance and advice to one another. For example, a mother who has cared for her child with cerebral palsy for many years, and has learned many skills and *tricks* in caring for her, can provide valuable advice to the mother of a new-born with cerebral palsy.

The standard CBR approach, devoted mostly to home visits, often does not do enough to promote information sharing between and among disabled persons and their families. The creation of a small community centre can help facilitate this process, especially when it is run by disabled persons and/or their family members themselves.

7. Work toward moving referral and technical services closer to the communities served by CBR: In many CBR programmes a wide, often unbridged gap separates the very basic front-line home-based CBR services and the distant, urban referral services. The result is that a great many disabled persons go without the rehabilitation and technical aids they need. To solve this problem, such activities as brace-making, prosthetics, wheelchair making, more advanced clinical assessment, testing of vision and hearing, non-surgical correction of contractures, and/or various types of skills training, can be carried out in the above mentioned community centres.

To carry out all these more highly skilled rehabilitation functions, local disabled persons can be trained in specially designed "hands-on" courses. These workers can be given modest but fair salaries, proportionate to what other semi-skilled workers earn in the community. The money for these salaries could be taken from that saved by not having to refer so many persons to the distant, expensive, urban rehabilitation centres. Such decentralisation of referral and technical services could in the long run be more economical and supply badly needed, and possibly more appropriate, services and appliances. At the same time it provides meaningful work for promising, young disabled person.

8. Encourage decentralised and egalitarian organisations of disabled people: The two most exciting and potentially liberating advances for the rights and well-being of disabled people in the last two decades have been firstly, the growing organisations run by disabled persons, together with the Independent Living Movement, and secondly, the Community Based Rehabilitation Movement. Each has its strengths and weaknesses.

- The strength of the organisations of disabled persons and the Independent Living Movement is that they are run and controlled

completely by disabled people who actively demand respect and equal opportunities in society. The weakness of organisations of disabled persons, in the South as in the North, is that both its membership and its agenda are urban-based and largely middle class. The poorest and most marginalised of disabled persons are not included for the most part.

- The strength of the CBR Movement is that its primary focus is on the poorest and most disadvantaged disabled persons, and that it reaches into their villages and homes. Its weakness is that too often disabled persons are passive recipients rather than active leaders in the rehabilitation process.

Greater co-operation between the organisations of disabled persons and community based rehabilitation programmes can help each of these important initiatives become more empowering in approach and more egalitarian in coverage. In a number of countries, CBR programmes have been started by organisations of disabled people. In other countries, CBR initiatives have helped disabled persons to begin to organise and take united action. Either way, disabled persons need to take a more active and leading role in the CBR programmes.

Conclusion

In closing, I would like to re-emphasize how important it is that *disabled children have role models of disabled adults who are successful, who are committed to helping others, and who have learnt to stand up for their rights*. When a family with a disabled child sees a team of disabled local persons *doing so much, so well for other people*, it gives both the parents and the child a whole new sense of what is possible. It awakens them to the changes that can happen when marginalised people join together, take charge of their lives, and demand equality.

It is essential that we disabled people help to design, and take the lead in *enablement* programmes that do not try to normalise us into an unjust society, but rather empower us to become leaders in the struggle for transformation. Together we must work toward a social order that provides all people - rich and poor, weak and strong, disabled and non-disabled - with equal opportunities, equal rights and equal respect.

David Werner is the author of *Where There is No Doctor* and *Disabled Village Children*.

Contact Address

HealthWrights
964 Hamilton Drive,
Palo Alto,
California, CA 94301
U.S.A.