
contact

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COMMUNITY-BASED REHABILITATION

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COMMUNITY-BASED REHABILITATION

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Illustrations included in this issue are step by step instructions to help children with disabilities to learn to move and balance.

PLAY WITH CHILD LYING ON STOMACH Stages 1-4

First Stage

- Encourage the child to raise their head, to support themselves on elbows
- Use padding where necessary



Fig. 1 'guessthesmell'

Second Stage

- Swing the child - slowly at first
- If the child is fearful, hold their body first

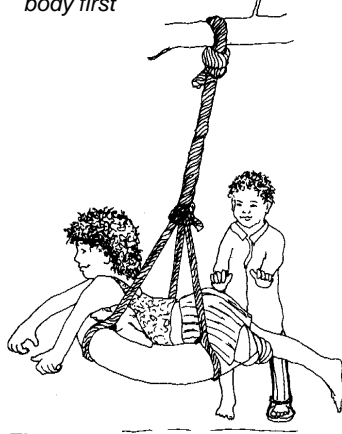


Fig. 2

Cover

One of the world's best known community workers – Mother Teresa encouraging a child

Credit: CMAI

It is now more than two decades since a slow but definite pattern of development has evolved in the field of disability and rehabilitation in what is now widely referred to as **Community-Based Rehabilitation (CBR)**.

While this effort could compare well with the Primary Health Care movement, it unfortunately has never received the same kind of attention or recognition.

This is not surprising since most of the disabled people in need of real help are from the marginalized sections of society. In addition, there is a small but rather influential, educated, urban middle class group of disabled people who do not need CBR and therefore can afford to be critical about it. Admittedly, some of their arguments against CBR may be correct, but given the fact that CBR programmes are almost indispensable for those living in urban slums or rural areas, their lobbying against it often thwarts important initiatives.

The importance of CBR cannot be over emphasized especially in settings where a large majority have no way out of their misery, hardship and discrimination.

People with little resources or support systems, like the mother with a child who has cerebral palsy in rural Bangladesh or a mine blast victim with spinal injuries from Ghana, are the ones who will benefit most from CBR.

This special issue of *Contact* focuses on the current debate about CBR. A debate, which recently gathered further momentum, with the announcement of the UN bodies to review their CBR programmes. This international review will take place in 2003 – the European year of the Disabled. With this special issue, we hope to bring to the fore CBR practices

within NGOs and church-based sectors. It is in these sectors that CBR has developed during the past few years without blueprints.

It is also a sector where CBR personnel have struggled to inculcate the essence of CBR participatory approaches. Activities have included a broader concept of community development and focus on the medical, educational, vocational, social and spiritual aspects of rehabilitation.

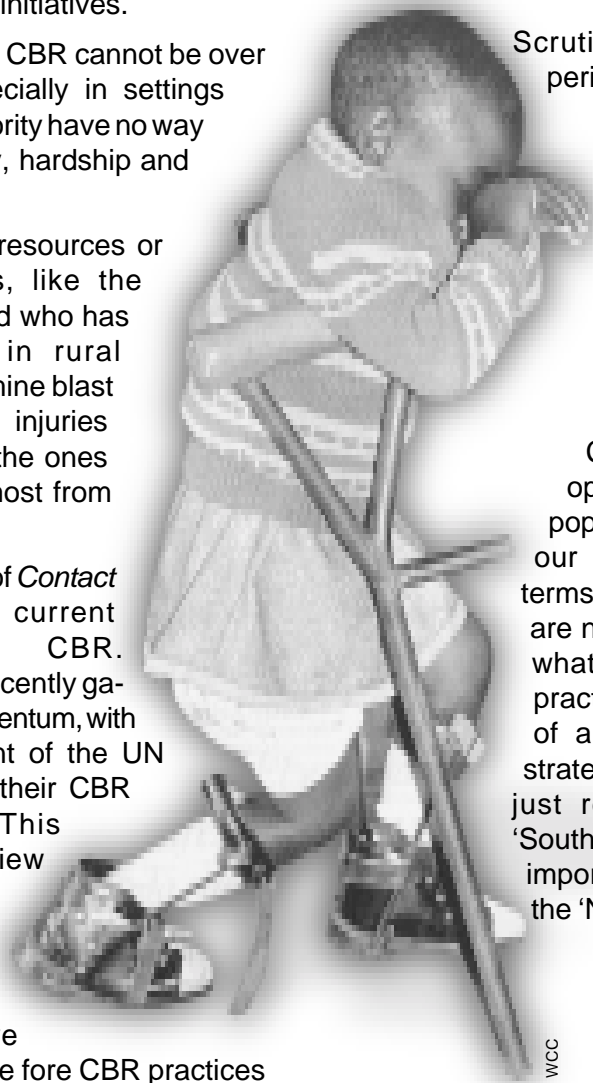
The various CBR models that were initiated by these sectors are forming an enormous resource for evaluation studies. But this resource is often not well documented and therefore remains unknown to policy makers.

It is hoped that the reflections in this issue will stimulate not only a debate, but will also form a catalyst for this sector to further improve the quality of work.

Scrutinizing the experiences of various backgrounds, sizes and scope will hopefully enable our readers to have a better understanding of CBR.

CBR in our opinion is gaining popularity. It is also our contention that terms and definitions are not important but what counts is the practical application of an attitude or a strategy which is not just relevant to the 'South' but is of equal importance to those in the 'North'.

Huib Cornielje
Guest Editor



WCC

WHAT IS COMMUNITY-BASED REHABILITATION?

Community-Based Rehabilitation is essentially meant to ensure that disabled people, wherever they are, are not discriminated against or deprived. M. Miles explains:

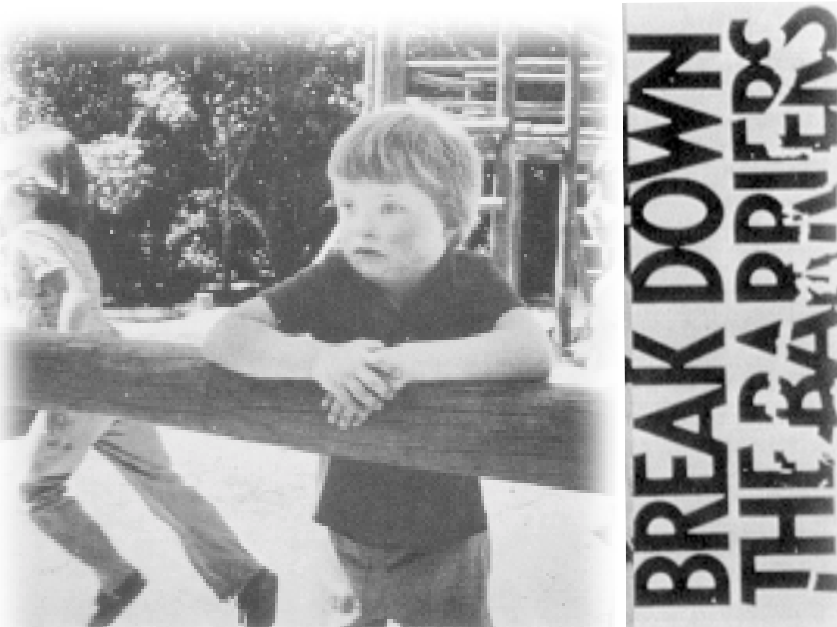
Introduction

For many people in the world now it is still a big problem to get help for their disability. City institutions are far away and cost too much. Even if you go to one, the help you get there may not be right for your home and family in the village, or in the poor part of the city. Some people ask, Why can't we have the best of both? Why don't we get the knowledge from specialists, and let people have it in the villages and towns where poor people live?

CBR

The idea of CBR is that disabled people should have the right to a good life. The help they need should be available to them, at a low cost. It should be offered to them and their family in a way that suits their usual way of living, whether in a village, a town or a city. They should have education like everybody else. They should be able to take up jobs and earn their living. They should be able to take a full part in all the activities of their village, or town or city.

The idea of CBR is that, even if people learn very slowly, or have problems seeing or hearing, or find it hard to move about, they should still be respected for being men and women, girls and boys. Nobody should be looked down on, or treated badly just because they have a



disability. Houses, shops and schools should be built in such a way that everyone can easily go in and out and make use of them.

Information should be given to people in a way they understand, not only in writing, which is hard for people who cannot read or have problems seeing it. Information should be given in spoken forms as well, so that **everyone** has a fair chance to use it. To do all this would mean a lot of changes. But they would be good changes, because everyone could live a better life, helping each other and respecting one another.

- Child reaching to play-thread bottle tops, pods etc. onto a piece of string

What is CBR?

“A strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities” (UN definition)

“CBR is a strategy for enhancing the quality of life of disabled people by improving service delivery, by providing more equitable opportunities and by promoting and protecting their human rights” (E. Helander).

Different ways to CBR

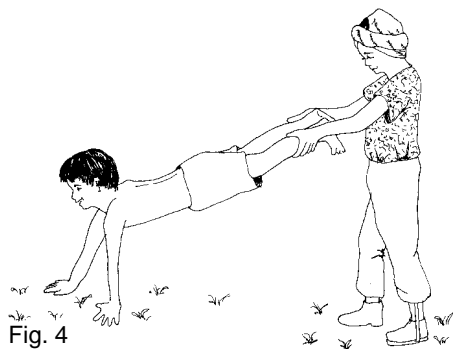
We began with CBR as an idea, which people use in different ways. In fact, CBR is a bag of ideas. Most people agree with the main idea, that disabled people should have a better life. But people have different ideas about how it should be done. Around the world, people live in many different ways, and have different beliefs about what



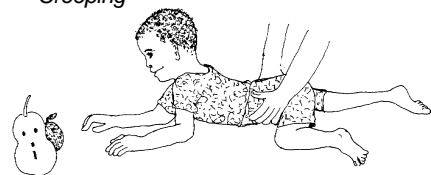
Fig. 3

Second and Third Stage

- First hold the hips, and then the legs

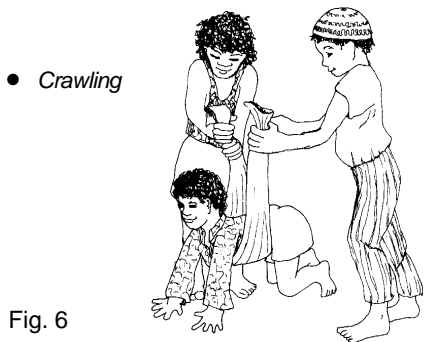


- Creeping



- Hold the hips. Rock the child from side to side

- Crawling



- Remember to check the child does not scrape arms or legs
- Use padding if necessary

people should do. So, people use the CBR bag of ideas in many different ways.

Some people think the government should take money away from the city institutions, and use it to pay for more people with healing and counselling skills in villages. Some people want specialists to go out from the city and travel round the villages, giving everyone a chance to see them. Some people want to send village healers to the city for training, so that they could go back to the village with a lot more knowledge and skills.

Some people say that we should listen and write down what each specialist says to a lot of disabled people. We would find that each specialist says some of the same things to all the disabled people they treat. We could put those things in a book, or in radio broadcasts, using simple words. Then many people could read or hear it for themselves. They could follow the advice at home, without needing to see the specialist. We could also collect all the good ideas that disabled people have, so that other disabled people could use them too. People who find it hard to tell what they want should have the

chance to talk it over with their families and friends and people they trust, to be able to say what would best help them.

Other people think that all this is a waste of time. They say that governments are made up of rich and powerful people, and will never do anything good for poor people. They say that poor people and disabled people should fight to get their rights. Nothing will be gained without a fight, with disabled people leading the way. There are also some people who do not like CBR. They say there are too many changes going on in the world. Maybe they feel pity for disabled people but they don't think anything can be done. They say, we never did this before, so why should we do it now? Other people have a different reason for not liking CBR. They say it is good to have institutions with specialists who get more and more knowledge, even if they treat only a few people. After a few years, their knowledge and skills will become widely available, by training students, writing books and making radio and television broadcasts. If you stop giving money to the specialists, they will never find any new methods or treatments.

Not easy

With so many different ideas, it is not easy to see what should be done.

To make changes in a whole country takes a long time. But people can start to make changes in their village, or in the part of the city where they live. People have been making small changes for several years. Disabled people are speaking up and saying how they would like to live.

Now they say it is time to move forward with CBR.

M. Miles, E-mail: m99miles@hotmail.com

Old Development Proverb

Go in search of your people, Love them;
 Learn from Them; Plan with them; Serve them;
 Begin with what they have; Build on what they know.
 But of the best leaders, when the task is accomplished,
 The people all remark:
 "We have done it Ourselves."

Updated Version

Go to the people; Live in a four star hotel several miles from them; Love them (but take care, they may have AIDS).
 Take from them their foolish customs;
 Start with what they lack; Make a list of what they need.
 But at the end of the day, When the work is still waiting to be done,
 The people will all say: "We are poor. We can do nothing."
 "Can you get me a job in your country?" "Please give us a big grant."
 "We badly need a Landcruiser." "Send the ticket and I'll come to Geneva."
 M. Miles (1995)
 Adult Education & Development, No.44, p.130.

THE IMPACT OF REGIONAL CULTURES ON DISABILITY

*Disability is not about being just disabled. Often peoples' attitudes are a serious hinderance to rehabilitation programmes. **Nora Ellen Groce**, an anthropologist, explains and analyzes the different ways in which societies have interpreted what constitutes a disability and what it means to be disabled. Excerpts:*

The context

The knowledge of traditional beliefs and practices towards disability is of vital importance if we are to plan and implement programmes for individuals with disability. Such knowledge can help establish what is universally true about disability and what is unique to specific

cultures. When specific cultures have positive practices these may provide models for more universal approaches to disability. When specific cultures have negative practices, change may be more effectively advocated when local people come to understand that their particular opinions and practices are not found world-wide.

Important issues

Culturally imbedded concepts of disability affect the way in which individuals with disability see themselves and the world around them. They also affect the way in which people around them — such as members of their family, their community, and their society — interact with them and they are the basis on which societies implement policies and programmes that directly and indirectly affect their right to play meaningful roles in their communities.

These beliefs are not always negative. But whether positive or negative, it is

Fourth Stage



Fig 7

- Creep and crawl under, up, down through, round things
- Crawling

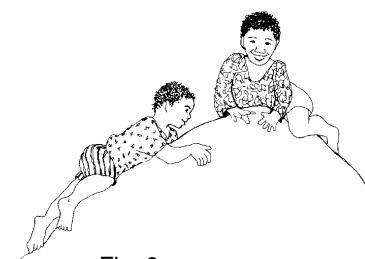


Fig. 8

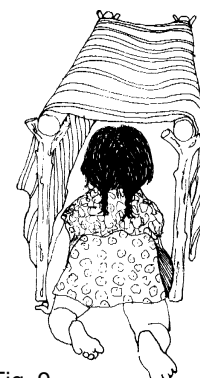


Fig. 9

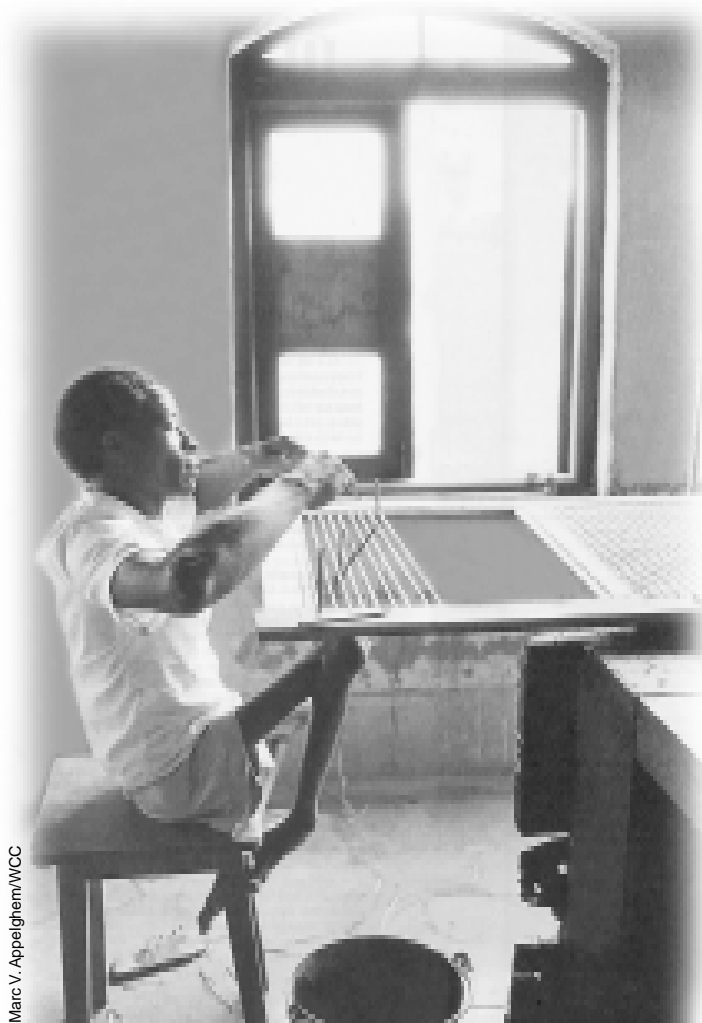




Fig. 10

Fill the containers with seeds, bells, pebbles etc.



Fig. 11

Disabled persons are affected by social expectations

necessary to understand them in order to effect change, either by addressing the negative models or by building on positive traditional models.

Discussion about disability, even in established western-based literature, is too often mired in sweeping stereotypes. 'Disability' as a concept, is rarely found in most traditional societies. Rather, societies around the world have tended to group together individuals with specific types of disability, such as 'the blind' or 'the deaf', and often have specific and very different ways of responding to individuals depending on what type of disability they have.

Although traditionally there may be broad categories such as 'the unfortunate', 'the infirm' and so on, the idea of disability as a broad category into which individuals with a diversity of physical, emotional and intellectual impairments are placed, is of relatively recent origin. This collapse of culturally distinct categories, which has become common during the past 50 years, has influenced

many of our initial attempts to look at disability cross-culturally.

In almost all societies, certain types of disability are far more acceptable than others. The acceptability of different types of disabilities do not seem, in a cross-cultural context, to be determined arbitrarily, but seem to be closely tied to how a society explains the appearance of that specific kind of disability. For example, in a society where it is believed that mental retardation happens by chance, but blindness is caused by sorcery, an individual with mental retardation may be easily integrated into the community but a blind person will be avoided by everyone.

Secondly, an individual with a disability is affected by what the social expectations are for such individuals when they reach adulthood. For example, in societies such as some in Oceania or New Guinea where the ability to speak eloquently in public forums is the way in which men gain power and prestige within the community, men with speech problems, hearing problems or intellectual impairments, will be at a particular disadvantage. However, women with similar impairments (or men and women with other types of impairments) may not face as severe social isolation or community discrimination.

In societies in which most adults must engage in substantial amount of physical labour in fields, individuals with mobility impairments may be at a distinct disadvantage. This does not mean that individuals with other types of disabilities, for example, deafness, do not encounter difficulties as well. It is only that certain types of impairments are considered particularly disabling when compared to others. In studies where western researchers seek to determine the social status of all individuals with 'disabilities', the difference in social expectation for one who is blind versus one who is mobility impaired, may be missed. However, in the real world, the need to understand where an individual with a specific impairment is located within a complex socio-cultural framework is



Didier Rueff/WCC

essential, if viable programmes are to be established.

Socio-economic inputs

Variables include, what group an individual with disability belongs to; the socio-economic status of the family, the gender of the individual and the specific socio-cultural roles and rights linked to gender.

To this must be added the variables of who the person with disability is as an individual, his or her level of education, chosen profession, marital status, and so forth, which will also make some difference in how he or she fares within the traditional cultural matrix. For example, if a poor widowed washer-woman with several children, living in the slums of Mexico City loses her vision, her lot in life may become exceptionally difficult. Even if her family can provide some assistance, the chances are that she and her family will struggle to meet their basic needs. If the wife of a prosperous local merchant, living a few miles away, loses her vision from an identical cause, her prospects for the future will be markedly different. However, the variables of class, marital status and economic stability will make an enormous difference in the choices each will have as they deal with their disability. Such expectations may be based on social expectation, not only of societal groups, but also of specific families and subgroups. For example, in the United States, it has been noted that many parents who are well educated and who expect their children to go to college, have more difficulty accepting a child with mental retardation than one with a mobility impairment.

Not constant

In studying traditional beliefs and practices, care must also be taken to ensure that socio-cultural belief systems are not viewed as 'static'. While many traditions and beliefs about disability are exceptionally long-standing and are intricately interwoven into many aspects of the local cultural belief system, it is important to understand that belief systems change over time. Often belief



Sesame Street, a U.S. TV show regularly included children and adults with disabilities. A Delaney

systems change rapidly when traditional systems intersect with western ideas and rapidly modernizing national and regional trends. Increasingly, people on all continents have some exposure to radios, televisions, movies, magazines and newspapers and these do have an impact on attitudes and habits.

Not simplistic

Unfortunately, attitude change for disability assumes a rather simplistic model for change. Although models such as Community-Based Rehabilitation focus on community-oriented change, for many international development agencies and national governments in the developing world, the assumption all too frequently, is that disability beliefs will move from traditional attitudes and practices to a western-based charity or medical model. In such a model, professionals from medicine and allied disciplines become gatekeepers to a host of largely institutionally-based services; it is a system that essentially further disempowers and disenfranchises individuals with disability.

The reality is more complex. People undergoing social change rarely

It is important to understand that belief systems change over time

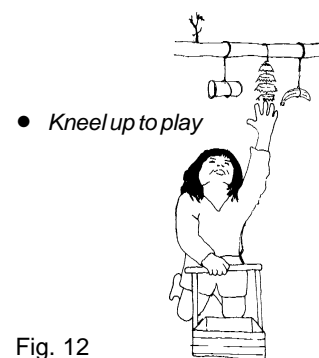


Fig. 12



Fig. 13

We need to understand beliefs, practices, customs and issues as part of a viable and interconnected set of systems

abandon everything they know and everything they practise, in order to unquestioningly adopt a new system of thoughts, beliefs and behaviours. Rather, as international health and development agencies are increasingly coming to realize, new and old ideas often co-exist and frequently co-mingle, producing hybrids that are neither wholly the old nor the new system.

To add to the complications of how new ideas and explanations are accepted, it must be remembered that not everyone in a society will take up new ideas at the same time. There will always be a vanguard of individuals who will accept and promote new ideas, such as the need to empower and include individuals with disability. There will also always be individuals, including many policy makers, who may be more keenly interested in maintaining a status quo.

Furthermore, there will also be some who waver between systems, such as those who in times of calm may give lip service to – and even believe in – progressive models of disability in society. When faced with the need to make decisions, particularly when it comes to prioritizing scarce resources or the transfer of power from established professionals and policy makers to those with disability or those who are otherwise disenfranchised, they may return to older and more dearly held ‘belief’ models.

No single answer

There is no single ‘right’ way to look at disability in society, but there is a wrong way. The wrong way is to mistake one’s own disciplinary training as the sole approach to a complex problem and with an almost missionary zeal, go forth to do battle with anyone who is not conversant in the tenets and terminology of one’s particular discipline. A different approach is not a less valid approach. The problem lies in the fact that all too few people stretch beyond the boundaries of their own disciplines or frames of reference to gather insight and information. We do not have to fully agree, but we need to be more knowledgeable about what questions

are being asked by other disciplines and what assumptions are being made, both by ourselves and by others. There is a need to think more creatively about how questions raised by other disciplines may also be of relevance to our own work.

Conclusion

Understanding traditional concepts and beliefs about disability are fundamental to our understanding of how to approach systems and how to foster productive change. But it must also be remembered that all societies change over time and incorporate new ideas into a cultural whole. Having said this, one cannot simply list what the traditional beliefs and practices are. We need to understand beliefs, practices, customs and issues as part of a viable and interconnected set of systems that are closely linked and often evolving over time.

To understand the complexity of issues surrounding disability in society, it is important to reach beyond the boundaries of our particular disciplinary and ideological frameworks, and seek productive dialogues with others using different disciplinary approaches.

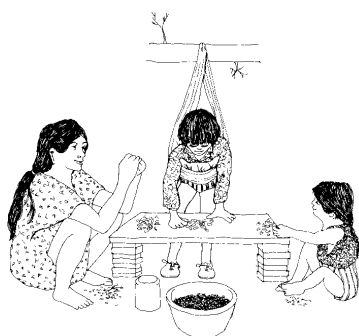
Finally, the responsibility and choice for how this new knowledge is to be used, and what changes may be promulgated or what traditional ideas and practices are to be kept, must ultimately rest with the individuals with disabilities within their respective societies. Disability issues are human rights issues. The more we can understand about the local concepts and beliefs about disability in different cultures, the more we can ensure that individuals with disability have a voice as we move with increasing speed into the 21st century.

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- Child supports on hands and feet



Fig. 14



- Sorting things for mother

Fig. 15

“...AM I NOT A MEMBER OF THE HUMAN RACE?”

*Society often has a blinkered view about persons with disability.
A first person account by **Muriithi Anthony** about attitudinal problems
encountered by him.*

I was not born disabled. When I was two-years-old a polio attack sapped my legs and I was unable to walk. My family and I were forced to slowly reconcile with my impaired limbs.

My parents soon prioritized the need to get me into a good special school. In 1984, I joined *Joytown Special Primary School* for the physically handicapped. But my memories of that place are not very pleasant. The food was inadequate and badly cooked, punishments for the pupils were severe and the workers were very unfriendly. In short, it was a place where I was made to feel that I was not a part of the human race.

I endured these hardships stoically and in 1991 passed the KCPE exams. I then moved on to the *Alliance High School*.

Fortunately, at the *Alliance High School* things were pleasantly different. For the first time I felt I was appreciated for what I did and was never ridiculed or ill-treated. The staff and the students were very encouraging and supportive. In 1995, I passed my KCSE exams and later joined the University of Nairobi.

Life on the campus was challenging. Even as I struggled with stairs, potholes and water shortages, I was also privileged to get a single room (other students have to share their quarters) and was provided with transport to and from lecture halls to anywhere in Nairobi.

Disability is not inability

Few people are sensitive or patient enough to understand a disabled person's problems. Daily life throws up numerous challenges and people like me are often at the receiving end of some misplaced sympathy or charity.

Not a beggar

One day I ventured into town to buy a radio. I was alone and a street boy who

happened to be disabled, offered to assist me. We went about together and eventually I identified a shop that I wanted to go into. I needed some help to climb the stairs to the shop and so called out to a shop assistant inside “Please can you help us?”

A man standing next to this assistant (probably the owner) reached for a shilling and told the assistant to give it to us.

I was appalled and hurt. What was I expected to do with one shilling when I had more than 3,000 shillings in my pocket and still could not get what I wanted? This incident highlights how most people tend to perceive the disabled as objects of charity. If a disabled person asks for help, one should ascertain what kind of help he or she wants instead of presuming that he or she wants your charity.

Wheelchair rut

On another occasion, I went to one of the supermarkets in uptown. Since I had been to the place before I was not apprehensive. However, to my surprise, a security guard came up to me and asked me to leave my wheelchair at the entrance and instead use the one supplied by the supermarket. This unreasonable behaviour really irked me. Changing wheelchairs is not an easy task. I told the guard that if I have to leave my wheelchair and use theirs then it was only fair that he ask everyone coming to the shop to leave their legs at the entrance and use another pair provided by the supermarket! I am not sure if the poor man understood my logic, but I am convinced that a lot of people are insensitive to the problems of the disabled.

Once I asked a man to help me with a flight of stairs. Although he obliged, he



Muriithi Anthony

PLAY WITH CHILD LYING ON BACK Stages 1-4

First Stage

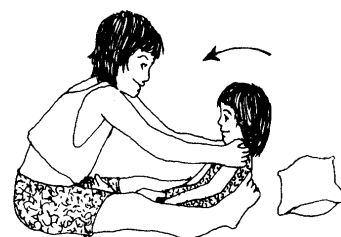


Fig. 16

- Encourage child to raise head
- Sing or call to the child



Fig. 17

Do not pull if child's arms are very weak or if their head falls back

“Give me a chance and I will prove that I am able. Give me a chance to learn, and to work and I will prove that I too am capable.”

Second Stage

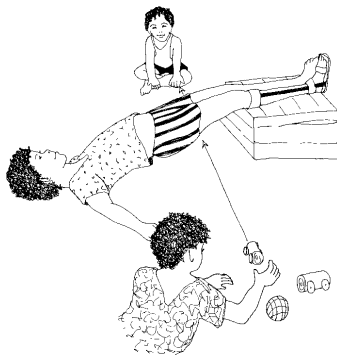


Fig. 18

- At first help the child lift their hips

was very rough and jolted me about in the wheelchair. As I thanked him I also asked him why he was so rough with me. He answered, "I did that so that you don't bother me again."

Of course, I was very hurt by his remarks and I regretted asking him for help. In fact since that incident, I rarely ask anyone for help, unless they are my close friends.

Other challenges

Apart from people's attitudes and behaviour, physically challenged people are put to a lot of discomfort as they try to negotiate around staircases or counters especially in public places like public telephone booths, ATMs, banks or railway stations. Most public amenities are 'disability unfriendly'. Some do not have ramps or lifts. Those that have ramps often have them built quite steep and without railings.

Even using public transport can be quite a daunting experience. Some public transport systems charge extra for wheelchairs. This to me is like paying for myself as well as my legs!

In addition, most assistive devices like wheelchairs, prosthetics, braces and hearing aids are expensive if not prohibitive.

Our needs

Most people dismiss disabled persons arbitrarily. Actually people with disability are very sensitive but ask for very little. In my opinion disabled people need:

Recognition – Recognize that disabled people are like everyone else; they have feelings and emotions.

Understanding – Understand that though they are like anyone else they have certain limitations and cannot therefore perform like able-bodied people.

Acceptance – Accept them for who they are.

Appreciation – Appreciate them and encourage them for their contribution however little it might be.

Lastly, **look beyond the disability.**

MURIITHI ANTHONY
 Courtesy: CHAKTIMES, Jan-April 2002 Issue

Guidelines to set up an income generating project for the disabled

Planning

- ❖ Analyze the situation. What are the actual needs in the community? What impact will the project have? What other activities have been tried?
- ❖ Decide on the objectives of the project; who will benefit, resources needed and the time scale involved
- ❖ Carefully consider risks that may affect the project
- ❖ Plan how to monitor and evaluate the effectiveness of the project

Participants

- ❖ Involve participants at every stage of planning, decision-making and running the project wherever possible
- ❖ Be realistic about the abilities of the participants
- ❖ Choose crafts that will involve

- teamwork and full participation by all
- ❖ Consider how people will be paid for their work. Guaranteed wages may seem a good idea but they may produce dependency.

Marketing

- ❖ What demand is there for your products?
- ❖ Who are your likely buyers – local people, tourists, overseas market?
- ❖ What sale outlets will you use?
- ❖ What transport will you need?
- ❖ Will you rely on charitable buying? Be aware this is a kind of subsidy and may not be sustainable
- ❖ Consider the competition. Will your project put other people out of work?

Raw materials

- ❖ Are materials locally available from a cheap and sustainable source?

- ❖ What is the environmental impact of using such materials?
- ❖ Is recycled material an option?
- ❖ Networking – can you link up with a similar project to buy materials in bulk?

Skills

- ❖ What skills already exist?
- ❖ Are there local craft workers who can help with training or volunteer their help and advice?
- ❖ Train staff well in all aspects including technical, managerial, financial and marketing to maintain sustainability.

Susie Hart has experience of working with craft workshops for people with disabilities in both UK and Africa. Address: c/o Crowther Hall, Weoley Park Road, Sellyoak, Birmingham, B29 6QT, UK E-mail: andythevet90@hotmail.com

A HEART FOR CBR

Laura and Douglas Krefting reflect on the CBR work of their Muslim colleagues and friends at CBR Development and Training Center in Solo, Indonesia, Center for Disability in Development and its partner organizations, Savar Bangladesh, Ministry of Social Welfare and Labour Muscat, Oman, and Comprehensive Disabled Afghans Programme, Peshawar/Kabul.

People often ask us what it is like being Christians working in conservative Muslim countries—Bangladesh, Oman, Pakistan and Afghanistan. We do not seem to have faced more challenges than any other CBR programmes. Because faithful Muslims pray 5 times a day, they understand and appreciate other ‘people of prayer.’ Many of our Muslim CBR colleagues at one time or another asked us to pray for them and we asked them many times to pray for us too. When working with a very disabled person where there was very little help available, we would all agree that the only thing we could do was support the family and pray. In our experience, committed people of faith, be they Christian, Muslim or any other religion, easily learn how to have the heart for working with the disabled people.

Minor differences

Of course, there have been some practical constraints in working in Muslim countries. In Afghanistan, the female CBR workers always had to be accompanied by a male relative. In many communities, it was necessary for the male CBR workers to take leadership roles while the women focused more on home visits. While frustrating for the very competent women staff, it did not really affect the quality of the CBR programme. We have also worked with people who gave all of their money to fake ‘pirs’ or religious healers trying to cure a disabled family member. This, though can happen in any religion. There are some very specific benefits to CBR in Muslim countries. Imams at the mosque have been very active in giving disability awareness through the Friday prayers. ‘Zakat’ or annual tithing money



Community worker encouraging children...

UNICEF

is often given to help the disabled people. Even the Muslim belief *Inshah Allah* — (It is God’s will) can be helpful in motivating families of disabled people.

One of the important lessons we learned from our Muslim colleagues is that CBR is about **giving people the heart**. CBR is not easy work and without some kind of feeling from the heart, many people quit after a few months. Below are some examples.

Experienced trainers

❖ One of the most important ways to ‘give people heart’ is to have trainers who are disabled themselves. For example in Bangladesh, Anika who uses a wheelchair because of *spina bifida* always taught this session about wheelchair use. The first time she would wheel into the class people would ignore her because they thought she was a patient. It was great fun to see their faces when they realized she was in fact their trainer.

Second to Fourth Stage

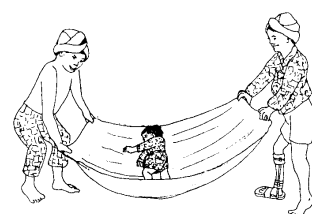


Fig. 19

- Roll and swing the child in a blanket - slowly at first



- Rolling down sandy or grass slopes

Fig. 20

PLAY WITH CHILD IN SITTING POSITION STAGES 1-4

Sitting Positions



Fig. 21

- Try many ways for the child to sit during play, stories and songs

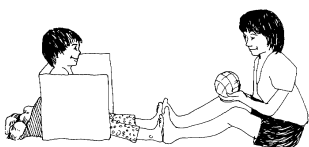


Fig. 22

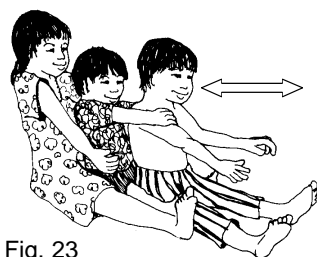


Fig. 23

- Roll back and forward, forward and back

In another case, Allam a CBR trainer with very low vision, always taught the sessions on blindness and his skill convinced the CBR workers that people with visual disability had great potential. Without saying anything, trainers with disability made the point that with help disabled people can succeed.

“Real experts”

- ❖ When teaching about a new kind of disability, we invite disabled persons (or their family members) who have that disability to be the resource people. We ask them to tell what it is like to have that disability and how other people treat them. We want the CBR workers to know the human side first. Then we give more details about the medical and rehabilitation part of the disability. We do not think of them as ‘cases’ (as they are sometimes referred to) but as experts. We give them the same honorarium as we do for doctors or heads of NGOs who give training sessions.

Role play

- ❖ We discussed attitudes about disability from the point of view of the *Quran*. This was useful to motivate the CBR workers and to promote attitude change in the community. Understanding how disability is viewed in the *Quran* (or any other holy book) helps people to understand why it is important to work with disabled people. Role plays are used to give the CBR workers information.

Introspection

- ❖ Another activity we use is to have CBR workers look at their own attitudes about disability. We ask people to answer specific questions

and without putting their name on the paper return them to the trainer. We then add up the ‘yes’ answers and ‘no’ answers and discuss the results of the whole group. Another example of this training technique is that we begin the mental illness training module with a questionnaire that looks at both knowledge and attitudes about mental illness.

If one day...

- ❖ In Bangladesh we used an exercise called *If Suddenly One Day* (adapted from a training technique developed by two American Maryknoll Sisters in Dhaka). We gave the CBR workers realistic situations and they discussed their own feelings and reaction imagining that it happened to them. We had a poster which shows different facial expressions and it helped people discuss the different kinds of feelings that people have.
- ❖ In addition, to help CBR workers to understand about exclusion, we used a comic strip which illustrated the stories of a social worker who walked by a disabled person every day and did not notice him. One day in a heavy rainstorm they took shelter together. The NGO worker realized that he had never “seen” the disabled person at all.
- ❖ The field experience includes informal sessions on the CBR workers’ reactions and feelings. CBR is difficult work and sometimes change comes very slowly.

These materials included here are on a CD called the CAHD ToolKit available from Handicap International. Center for Disability and Development.

Laura Krefting has worked as a trainer in the CBR field for 12 years in several countries including Indonesia, Bangladesh, Nepal and Afghanistan.

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D. Mangurlian

A girl with artificial hands learning to weave.

MOTHER PARTICIPATES

*Given Bolivia's fragile economic status, specialized care for disabled children is almost an impossibility. San Juan de Dios Hospice Order hit upon an unique idea called 'The Mother Participates' where both the mother and her disabled child are called for a two-week, in-house training. This pilot programme which has been in operation for four years has been largely appreciated. A report by **Elieane Ballerstaedt**:*



World Rehabilitation Fund, Inc.

Introduction

The **Mother Participates** is a programme which is committed to avoiding disabled children from being taken from their family home and community. Instead it aims to provide support for the family while it adapts to having a disabled child at home; and principally, to take the family into consideration during the rehabilitation of the disabled child.

The team at San Juan de Dios are trying to change the perception that disabled children are 'ill' and are trying to work towards a less 'medical' and more 'social' treatment of the problem.

All over the world, there is a trend towards trying to avoid taking disabled children away from their family and therapists are increasingly taking an interest in the idea of encouraging the active participation of mothers in the whole process.

In Bolivia especially, this way of dealing with disability is more coherent than the previous method of putting all disabled people into specialized centres.

For a poor country, with precarious health services, it is almost impossible to maintain such centres in a good condition. But there is no doubt that the main problem is the way that families are torn apart when a child is taken away at a very young age and placed in an institution. The emotional ties that bind the members of the family are broken and the child grows up to become a lonely adult, without a family, until, at the

age of 18, he or she returns home or is admitted to another institution, this time for adults.

Angela and Rosalia

Angela and her daughter Rosalía, who has severe cerebral palsy, are from the countryside and visit a hospital recommended by the nurse at their village health centre.

They are both frightened, do not know anybody and Angela only speaks 'Quechua'. It is not easy for her to ask questions and, it seems that not many people can understand her. Rosalía observes everything carefully with her big dark eyes. The only word she knows is 'mummy'. She cannot speak, but those brilliant eyes are able to say many things. They are full of curiosity and fear. Rosalía senses that something is wrong because her mother was crying throughout the journey.

Angela is a single mother and lives with her family in the countryside, helping to grow potatoes. It has never been easy to look after Rosalía, but at least she could carry her daughter in her 'quepi' and take her into the fields where she worked, about three kilometres from their home. However, the child has grown and, having recently celebrated her fifth birthday, she is getting too heavy to carry.

No better teacher than a mother.

Sitting Positions



Fig. 24



Fig. 25

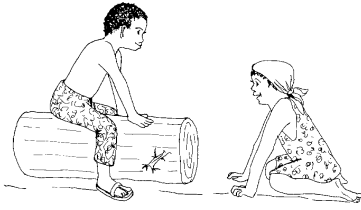


Fig. 26

She does not want to leave her daughter, but neither can things carry on as they are. What should she do?

Nobody stays at home during the day, everybody goes into the fields. But her daughter cannot stay on her own for hours on end. She cannot even sit up on her own or change her position.

That is why Angela had asked the village nurse for help. The nurse had contacted this hospital, where many children like Rosalía live. The hospital that they are hoping will help them, is called *San Juan de Dios*. It is more a nursing home for children and young people than a hospital. It is managed by the 'San Juan de Dios Hospice Order'.

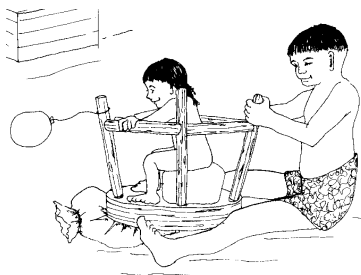


Fig. 27

The Order also manages the biggest and, until recently, the only public psychiatric hospital in this country.

Just like Rosalía, many children arrive every day from different parts of the country, with parents who intend to leave them there permanently as patients and visit them perhaps once or twice a year.

Many families are confused about their child's disability. They find it difficult to deal with the disability and think that admitting their child to the hospital may be the best solution. But, as in the case of Angela, in their hearts, this is not what the mothers really want.

A pilot programme

With this in mind, the organization set up a pilot programme – 'Mother Participates' – as an alternative. A physiotherapist and a language therapist will work with Rosalía but will also teach Rosalía's mother – in her own language – a series of exercises and positions that will help her daughter to develop her potential. The therapists will monitor Angela's progress and Rosalía's response on one or two return visits and adjust

the exercises accordingly. The idea is not just to teach the child to move about and sit up, but to be more independent and to participate in the activities going on around her.

In addition, various ways of making a wheelchair from household materials will be explained. If necessary, the institution's wheelchair workshop will design a low cost wheelchair.

After a week's intensive training, Angela and Rosalía are allowed to go back to their village, but will have to return in two months for an evaluation. New exercises and postures will be taught if necessary.

Angela is also given a letter to hand over to the nurse at the community health centre. This has the information the nurse will need to monitor the child's progress during home visits. Angela is also encouraged to visit other children with similar problems in her community and help them with skills she has learnt.

Reassurance & relief

Angela learns that her daughter will slowly sit up, and perhaps, with a lot of work and effort, also eat by herself, though this will not be easy. Angela did feel, however, that it would have been better if the child could have been seen regularly by a professional therapist until she managed to achieve these things.

But Angela now also understands that her little daughter is not 'ill'. Though she is different from other children and always will be, she accepts the disability. This has taught her to deal with her daughter's needs as she grows.

The main thing is that Rosalía will continue to live at home with her family and will not have to experience the trauma of being shifted to a strange place.

Depending on the financial support it receives, in the near future, the 'Mother Participates' programme hopes to visit rural communities, in order to evaluate and serve the community.

Elieane Ballerstaedt, Bolivia



World Rehabilitation Fund, Inc.

RESTORING HEALTH AND DIGNITY

The Danish Bangladesh Leprosy Mission (DBLM) has been providing leprosy control and treatment to four districts in north west Bangladesh for nearly 25 years.

Robert Bowers and Sherilyn Bowers narrate the change in trends and the decline in new cases due to early detection and treatment. There has also been a corresponding decrease in disabilities from leprosy.

History and structure

The *Danish Bangladesh Leprosy Mission* is currently managed by The *Leprosy Mission International* (TLMI). TLMI and the *Danish International Development Agency* (Danida) jointly provide funding for the project. Currently, the leprosy control project covers 4 districts in the extreme north-western corner of Bangladesh, serving a population estimated at 6.3 million people.

Founded in 1977 by the *Danish Santal Lutheran Mission*, DBLM began with fieldwork in two districts and a central hospital covering the two other districts. These four districts have the highest incidence of leprosy in Bangladesh. In 1997 control of DBLM was handed over to *The Leprosy Mission International*.

Rehabilitation programmes

A recent evaluation made it clear that DBLM was doing more rehabilitation work than its reports revealed. The current definition of rehabilitation at DBLM has therefore evolved and is:-

“...the restoration of an individual to their previous physical and mental condition (assuming there was a time-limited disease process) OR the integration of an individual fully into the community for the first time (assuming there was a chronic condition).”

Given this definition, the total rehabilitation process must include three parts:

- **Education** of the individual, their family, and the community
- **Medical-based therapies**



Media and People with Disability

- **Economic** assistance as a motivator against social stigma

Some components of this process are primarily centre-based while others are primarily community-based. DBLM is working slowly but deliberately, to shift the balance of control toward the community. This necessitates empowering the community with the knowledge and skills required to take ownership of and responsibility for their members' needs.

Education

Education is a crucial aspect of transferring control of rehabilitation out of the institution. The front line in the leprosy control work of DBLM is the army of field staff. There are nearly 100 field workers who live and work within small geographical areas, engaged in case-finding, education, and patient follow-up. They have well-established relationships with the people they serve.

- Dig a hole in the sand for the child's bottom and heels



Fig. 28



- Sit in tyres filled with grass, paper or rags

Fig. 29

First Stage

- Try different positions - as you advance through the stages give less and less support to the child's body
- Encourage the child to raise and hold up head



Fig. 30

- Help the child to sit upright
- Rock child backwards and forwards to a song



Fig. 31

This network is already used for leprosy education, and is ideal for further education in general rehabilitation as well. The education process is vital for reducing the stigma associated with leprosy or other disabilities. In addition, the field staff has an important role in advocating for patients within their communities.

Therapy

Medical-based therapies, primarily physiotherapy, is essential to any comprehensive rehabilitation programme. From the time of DBLM's establishment, physiotherapy has been one of the services provided at the main hospital. The experienced physiotherapy staff provide post-surgical care for the patients undergoing reconstructive procedures. They also perform regular sensory evaluations and provide education programmes for patients, in order to prevent further injuries. The physiotherapists cannot, however, meet the overwhelming needs by themselves. Thus, the field staff carries out routine physical rehabilitation care within the community. The field staff also provide education and training to patients and their communities in meeting physical needs.

Another component of disability in leprosy is significant social stigma. Persons affected by leprosy are often abandoned by their families, their employers, and their communities. This stigma, while formerly due to fear of the disease itself, is now primarily related to the presence of physical impairments. The advent of MDT and extensive community education has improved this situation, but it persists for many people.

Socio-Economic Rehabilitation (SER)

In the early days, the expatriate staff became increasingly aware of the financial needs of many of the patients. This realization became the impetus for the beginning of the socio-economic rehabilitation (SER) programme at DBLM. Initially, individual needs were met by the private gifts of expatriate staff. However, the project was rapidly expanding, and individual staff could no longer meet the overwhelming needs. At this time, part of the budget was assigned to address these socio-economic needs.

In the first 20 years the emphasis of this programme was on individual monetary grants and centre-based vocational training projects. In the past five years, however, there has been a deliberate transition away from grant giving toward small-scale, low-interest or no-interest loans. The field staff primarily manages these loans. The project has also increased its emphasis on the development of new vocational training programmes, both in the community and within the institution.

Beggar's club

DBLM has started a number of different community-based micro-credit, savings, and/or education groups. The 'beggar's club' is a good example of how these groups can move control of the rehabilitation process into the community. A group of beggars meet regularly to encourage saving, to give small loans to each other, and to help one another plan for the future. The group also monitors their members for wounds and other consequences of their

Ansura is from a small village in Bangladesh. When she was eight-years-old she developed pain and swelling in her right knee. As is the local custom, her parents first took to the village doctor for treatment. The quack, after many pot shots, one day gave her a 'medicine' which made the child go into a coma. Her alarmed parents then rushed her to the local government hospital, and after three long days, she regained consciousness. For the next four months, doctors at the hospital attempted to heal Ansura's leg, without success. Finally, an amputation was recommended. Her father however, was not ready for this radical solution and so he brought her home. Some months later one of our tuberculosis /leprosy workers (TLW) visited the village for community education. The girl's father described his daughter's condition. The TLW suspected bone TB and suggested meeting the doctor. The doctor instituted a 6-month course of TB medicines. The leg improved significantly, but Ansura later had to undergo surgery at DBLM's primary hospital to remove some dead bone tissue. Now, Ansura is a beautiful young woman. She still has weakness and pain if she uses her right leg too much. This persistent disability makes it impossible for Ansura to perform manual labour, so she has been admitted to DBLM's tailor training programme.

leprosy. In at least one instance, group members encountered an individual who appeared to have leprosy in its early stages. They took responsibility for this member of their community and insisted he go to a clinic for diagnosis.

Future plans

With the number of leprosy patients on the decline do we now gradually shut down? Do we shift focus? After considerable discussion, it was decided that DBLM would gradually start transitioning into general disability treatment and rehabilitation. Services for the disabled are extremely limited, and are often difficult to access, especially in this remote region of Bangladesh.

In early 2000, two of our physiotherapy technicians were trained to attend general disability. Building on those skills DBLM has been offering a general disability clinic for children for the past one year. So far, 180 children have been seen in this clinic, and there are plans to open another clinic this year.

Last year DBLM began offering our socio-economic services to a limited number of poor people with general disabilities. In the past, economic aid (vocational training and loans) had been offered to any poor patient who had been diagnosed with leprosy and/or TB. Recipients were not required to have a physical disability or social handicap.

Thirty-year-old Abdul was diagnosed and treated for leprosy. At the time of his diagnosis, he worked as a labourer and earned about 13 Bangladesh Taka per day (less than US \$0.30). While he was going for his treatment, Abdul's wife left him and took their nine-year-old son too. Ostensibly, this was because he had leprosy but it is possible that his poor wages was a contributing factor. To make matters worse, Abdul also developed a foot drop – a complication caused by his leprosy. Within a year, Abdul had surgery at DBLM to correct his foot drop, and received physiotherapy services to retrain his transplanted muscles, thus meeting his physical needs. He then began training in DBLM's bicycle repair programme to meet his economic needs. To help Abdul combat social stigma and discrimination, DBLM's field staff rallied around and educated the community. This paved the way for acceptance and four years later, even his wife and child returned to him. Abdul now has his own small shop beside a bus stop on a major highway. In addition to repairing bicycles, he has purchased several bicycles, which he rents out on a daily basis. His average daily income is now around 60 Taka, which is just over US\$1.00. Though this is still low to western standards, it represents a significant improvement, and allows his family to make ends meet. Thanks to DBLM, Abdul has a new life.

Beginning this year, DBLM plans to add the presence of disability and/or handicap as a criterion for receiving SER assistance.

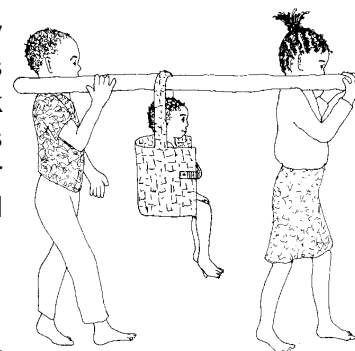
Conclusion

Since its inception, DBLM has gradually introduced rehabilitation programmes as needs became apparent. The network of field staff, clinics, and hospitals provides the ideal framework for continuing the shift from centre-based care to community-based care.



Robert L. Bowers, MS, Rehabilitation consultant for The Leprosy Mission Bangladesh, works primarily for Danish Bangladesh Leprosy Mission. Sherilyn S. Bowers, is a Occupational Therapist. E-mail: bowers@tmbangladesh.org

Second and Third Stage



● *Swing the child*

Fig. 32

● *Rock from side to side*

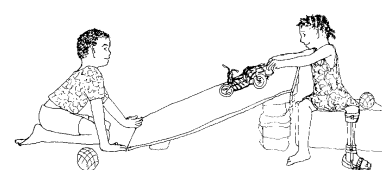


Fig. 33

SPECIAL SCHOOL FOR SPECIAL CHILDREN

A small project supported by the Christian Blind Mission on the fringes of south-east Nigeria makes a definite impact on the community they serve. Frank van der Maas reports:



We started in 1992 by employing a secondary 'school leaver'. He went to all the primary and secondary schools, village meetings, church gatherings and educated people about different disabilities.

This paved the way to understand the most urgent needs in the community and tailor some activities for them. These include programmes for :

- Hearing impaired children.
- Visually impaired children and adults.
- Physically impaired children and adults.
- Vocational training.

We started by accepting some hearing impaired children – one per week – to receive some basic lessons and we started some vocational training in the village.

In 1999 we started a **Special School for the Deaf**, with 16 students. The students live in independent compounds, scattered in the village for complete integration. Since there was no help for hearing impaired children before, we have children of all ages in the school. This however is not any problem. The older students take care of the younger ones and the younger children help the older ones in cooking, fetching water, firewood etc.

When we started the school we had to convince most parents the need to educate a deaf child. Many parents refused to allow their child to come to the school. Presently we have 52 children and many are on the waiting list.

We sent each student for an ear test in town before starting school. Later, we got an audiometer and started our own tests. Many children came to be tested

in our audiology unit and were advised about medicines or about school admission.

In 2001 we started a programme called **Total Communication**. The curriculum includes sign-language, speech-therapy and lip-reading which are taught by teachers who are trained in this field. This has encouraged the children to interact more freely and take part in activities in the church, as they can communicate a little with the other children. This interaction has also helped many families to familiarize themselves with sign-language.

The school also insists that parents must attend the monthly parent-teacher-meeting, where they too are taught sign-language. Sometimes a brother or sister of the deaf student is encouraged to live with other deaf children so that he can later help his parents to understand the deaf child better.

The school follows the same syllabus as the government run village primary school.

Department for Visually Impaired: An eye-doctor visits the centre once every 2 months for consultation and operations. On an average he consults 120 patients and operates 25 patients per visit. A worker trained in Basic Eye Training assists the doctor.

The patients pay for the operation and only when they cannot afford it do we help them a bit. In cases where the

Third and Fourth Stage



Fig. 34

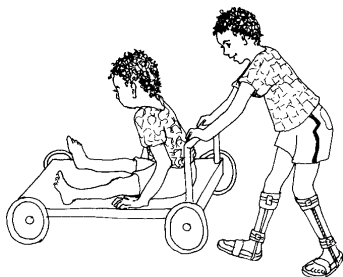


Fig. 35

patients cannot afford treatment we offer them eyeglasses at reduced prices.

If the patient is totally blind, we visit him/her at home for training (orientation and mobility). This work, though very time-consuming, is worthwhile and the patient appreciates our concern.

In cooperation with Global 2000, we distribute *Mectizan* every year in more than 60 villages to prevent River-blindness. This drug is free of cost. We train two persons per village to distribute medicines to each person in their village. The village decides how to reward them for their work (e.g. by giving some yams, exemption of tax or village work).

A few children are supported in a Special School for the Blind in the town. The children receive financial support for the school fees, but the parents take care of the food.

Department for physically impaired:

An orthopaedic doctor visits the programme regularly for consultation and operations on orthopaedic patients. On an average he consults 70 clients and performs 15 operations mostly on clubfeet, osteomyelitis and fractures. Some workers in this department are trained in basic physiotherapy and they are responsible for dressings and Post Operative Physiotherapy (POP). After the client returns home, the worker continues with home visits and instructs the family on how to assist with the exercises. All the materials we use for aid are made from local material, like bamboo, wood etc. The book "Disabled Village Children" from David Werner has been very useful to us.

Some local bicycle repairers, shoemakers and carpenters have been given basic training on how to make callipers, crutches and orthopaedic shoes, and they help the patients. Even wheelchairs are made locally in the village; and this helps to reduce the cost and makes it easier to maintain.

In addition, some people are helped with vocational training to be able to earn some income. We teach them to weave chairs or help them to start a small grocery shop.

Educational and vocational rehabilitation

We try to let the disabled person be as independent as possible. We also encourage him/her to go to a village school where we sometimes have to intercede with the management for he/she to be accepted.

In other cases we liaise with local tailors, carpenters, shoemakers, bicycle repairers etc. for apprenticeship. The patient is trained with them for one or two years. On completion of the agreement, he/she is encouraged to start on their own. Loans are also given to help them to get a head start.

Income generating programme

Finally disabled persons are also involved in our **Income Generating Programme**. Our handicapped children help in the production of articles like detergent, vaseline, butter, soap, powder, weaving of chairs, postcards etc.

They also market the articles in the different villages. We get a little income from this but it serves to build up awareness, for the disabled person in the shop has a good opportunity to get involved in the society.

Awareness

Our staff goes out regularly to different places to educate the villagers. This helps to change attitudes and to prevent handicap etc. They also visit schools (early case detecting), village gatherings and women's meetings. The church has a special day (twice a year) on which the preaching and the collection in the churches are all focused on the CBR programme.

The community has been very supportive towards the programme. The small office and the classrooms for the school for the deaf are all built by the villagers. The village has donated the land and the older students of the village made the playground in the market.

Frank van der Maas, CBR Ephphatha, PMB 49, Abakaliki, Ebonyi State, Nigeria.



Fig. 36



Fig. 37



Fig. 38

A BREAKFAST TO BREAK BARRIERS!

*A disabled person is not one who is just physically or mentally challenged, but sometimes socio-economic and emotional problems can limit the person's participation in routine activities. Drug addicts are a case in point and **Leonardo Villegas Zamorano** narrates a community's innovative way to help rehabilitate these young people.*

PLAY WITH CHILD STANDING Stages 1-4 and later

First Stage



Fig. 39

Second Stage



Fig. 40

- Bounce the child on a sack of leaves, sand, straw

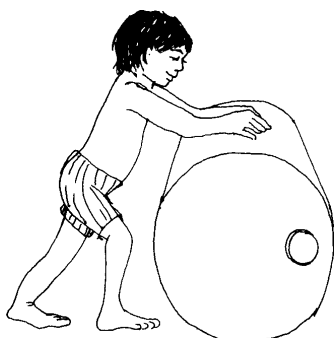


Fig. 41

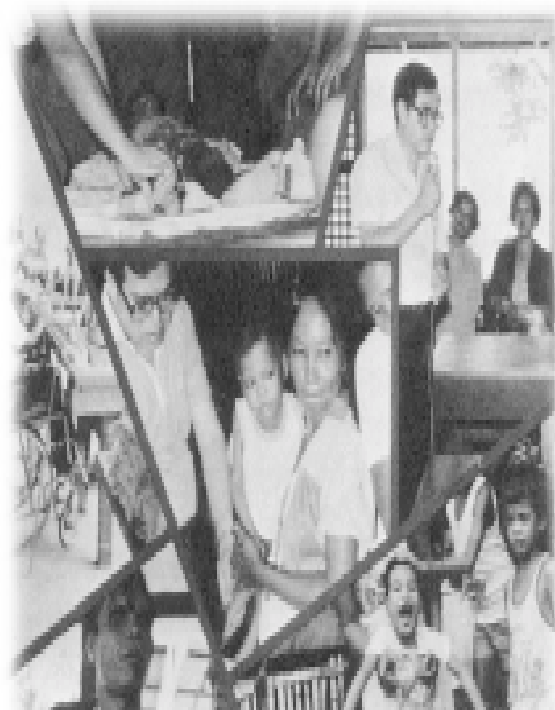
Santiago in Chile may not be a popular tourist destination but it is a vibrant city with a charm of its own despite the poverty and other problems. However, La Legua, is an area that most people would strictly recommend not to visit. Notorious for its drug cartels and prostitutes most sane people would prefer to stay away from this dangerous neighbourhood.

The Legua, like other working-class pockets that dot the city of Santiago, has a population of 27,000 inhabitants mostly service employees and informal workers. Their socio-economic status brings with it the usual problems like poverty, unemployment, delinquency, alcoholism, broken families, child prostitution, and the use of drugs. Besides the early erosion of values, it is the increasing numbers of children taking to crime that is causing alarm. Ten-year-old boys are openly pedalling and using marijuana/crack and pre-teen girls are into prostitution. Drugs have destroyed entire families, corrupted the youth, sullied and altered community life completely. Consequently, the area has fallen into disrepute and people living here face discrimination.

But though the shadows are long and lingering, light has not gone out completely. A small group of motivated and committed Christian youth from the same community have stepped forward to set right the wrongs.

'Breakfasts for Jesus'

'Breakfasts for Jesus' was just the first step. Sensitive to the marginalization



Community support is essential for rehabilitation.

Improving Communications about People with Disabilities

and suffering of many young drug addicts, this group hit upon the idea of baking a supermarket cart loaded with sandwiches, coffee and tea for those who were out on the street corners indulging in drugs and were without breakfast.

Every Sunday morning, they scour the alleys and streets between six to ten in the morning and reach out to young people, many so 'stoned' they that do not even realize that they are hungry.

Most young people who come for breakfast are between 18 and 35 years and are usually a dishevelled lot with obvious signs of physical, psychological and social abuse. Most of them are abandoned by their families, sleep on the streets, show high levels of malnutrition, and have records of delinquent conduct such as robbery and assault.

The positive fall-out of this exercise was that it helped to establish contact with young drug consumers. Drug addicts as a rule reject 'outsiders' and tend to be reclusive, but because of this initiative, some of them started to talk and share their problems, which in turn made them open to accept help. This paved the way to introduce a change of attitude toward life and slowly encouraged them sign up for help with rehabilitation.

'Young Man, Arise' – a therapeutic community

This therapeutic community was born out of concern to check the increase in drug intake amongst the youth. Since drugs not only destroy them physically but also condemn them to a life of anguish, rejection and loneliness, the importance of support and encouragement to help them break free from this vicious set-up was underlined.

Inspired by Jesus's command "Young man, I say to you, rise!" (Luke 7.14), the therapeutic community 'Young Man, Arise' was formed. It welcomes all drug addicts into its fold and motivates them to shun their limitations and to get up and walk free and with dignity.

It is a place of encouragement and takes care to reinforce the young person's commitment and will to change, besides empowering them to use their own resources to face the process of rehabilitation.

Drug users and addicts are welcomed into the community and treatment is accorded in keeping with their personal characteristics and their history of drug use, through either residential or ambulatory treatment. The rehabilitation process lasts approximately 8 months in which the young person goes through different stages (detox, integration, confrontation, assimilation etc.).

Many of those who come for treatment do so because they have "hit bottom," and describe this feeling as one of total destruction, having lost everything, being nobody, losing respect for their own families to the extent of stealing from them or hurting them.

Once they start treatment, they slowly start to rebuild their lives. They recover their weight, re-learn about hygiene and health, and re-establish ties with their families. They also learn to participate in individual and family therapies, group activities and acquire habits, norms, and manual abilities through labour and craft workshops. This way they are slowly able to move to higher levels of self-knowledge and self-control for their future family, work and social reintegration.

Both *Breakfasts for Jesus* and the therapeutic community *Young Man, Arise* are real experiences of health and human promotion which emerge from the community itself. There is no formula for change, but by taking one day at a time and trying to rebuild what is shattered, there is hope.

Leonardo Villegas Zamorano, Therapeutic Community Coordinator, 'Youngman, arise', Santiago, Chile.

Third and Fourth Stage



Fig. 42

- Help the child bring hands together and reach



Fig. 43

- It may be easier for hands to come together in this lying position



Improving Communications about People with Disabilities

WOMEN OF COURAGE

*A simple story-telling workshop spins hope to a number of disabled women. **Theresa Lorenzo** narrates the powerful experience:*

Introduction

In 1998, disabled women participated in story-telling workshops over a period of six months, as a collaborative participatory action research project. Initiated by the Department of Occupational Therapy at the University of Cape Town together with Disabled People South Africa (DPSA) Provincial Disabled Women's Programme and the South African Christian Leadership Assembly (SACLA) Health Project, a non-governmental primary health care project. Disabled women shared their stories of social and economic development. The participants came from rural areas of the Eastern Cape (approximately 1000km from Cape

Town) and lived in wooden shacks in the semi-urban areas close to Cape Town. Most of them were single mothers who looked after more than just their own children.

The platform

Since May 1999, they meet each month to look at social issues of health, education, transport, and employment related to disability within the family context. A series of workshops based on participatory action research used story-telling to break their feelings of isolation and build a strong sense of identity both at the individual and collective level. This process underlined the old African philosophy of Ubuntu: "*Umuntu ngumuntu ngabantu*" A person depends on persons to be a person. Disabled women found a new inner strength and no longer felt sorry for themselves. There was also an increased awareness of the abilities and limitations. They saw themselves as providers and have shown a strong motivation and desire to be successful.

Strength to break isolation

The sense of isolation that disabled women experienced was broken through these meetings where they shared their stories. Group activities forged strong bonds and help them to gain self-confidence.

"I used to sit at home and feel sorry that I am disabled. But when my rehabilitation worker brought me here I saw that I was not alone."

Regular meetings with one another helped disabled women to recognize how they were undermining themselves as well as being undermined by others. As one woman shared: "I never believed in myself."



Improving Communications about People with Disabilities

A disabled person working together with other workers in an umbrella factory in Addis Ababa, Ethiopia



Big Cat Marketing Communications

home and I see myself as a light. I'm the light for other disabled people and I'm not afraid of that and I talk about it."

SACLA — agents of change

There was appreciation for the role of SACLA's community rehabilitation workers — themselves mothers of disabled children — as agents of change:

"I've got a certificate now and I can now get a caterer's job. I didn't know that I could be taught and be educated. I used to just look at restaurants, not having anything to eat but now thanks to SACLA, I can also do those things that they are doing there."

A similar experience was shared by a mother of a disabled child:

"I was always sitting alone in the house feeling sorry about my disabled child. But as soon as I started working for SACLA I gained confidence."

The disabled women also recognized the role of the community rehabilitation worker in providing support: "When I became disabled I felt very sad but these rehabilitation workers came, and supported me."

The value of training parents of disabled children who are from the same cultural background was evident as similar experiences were exchanged. From their own experience of disability as women and mothers of disabled children they were able to relate to the experiences of other disabled women.

Fostering growth

Through their active participation in creative activities during the workshops disabled women shared how the group helped to foster the growth of their personal ideals and aspirations. The group felt that the programmes organized by SACLA and DPSA should continue as they recognized that these were beneficial in fostering their growth in self-confidence.

Disabled women showed that they were agents of change as they asserted, "We want to develop ourselves." There is a

Third and Fourth Stage - contd.

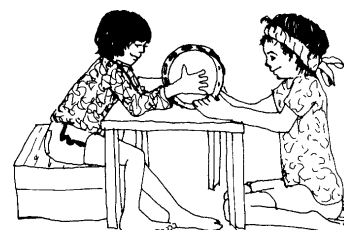


Fig. 44

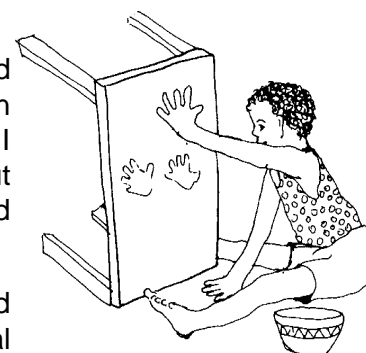


Fig. 45



Fig. 46

Self-confidence replaces self-pity

"When I became disabled I always undermined myself when I was with my friends. I always sat in one place. But when I met other disabled people I became stronger and no longer feel sorry for myself."

"Before, it was dark and I didn't want to accept my disability, When Lindiwe (social worker) introduced me to the group, I was happy and I became one of them. I could do things with my hands and now I have a certificate."

Renewed sense of power

Another significant change noted through the series of workshops was the experience of 'strength' or a renewed sense of power. They were now able to see themselves as providers of light to other disabled women as they had regained their dignity as women.

"I see change so now I'm well, but it's sad when you see others having problems. I'm a tower of strength at

- Take and grasp in different ways



Fig. 47

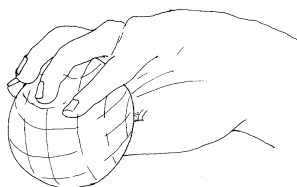


Fig. 48

- Play with larger things first



Fig. 49

Drop things into large containers first and small containers later

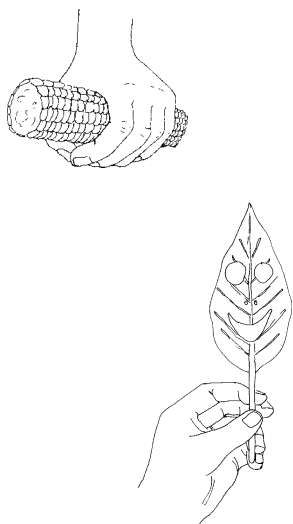


Fig. 50

Caution : Be careful - stop baby putting small things in mouth

Credit: All Illustrations by Shona Grant, AHRTAG

growing sense of self-confidence and self-worth reflected: “we are even better” and we can do even more than able-bodied women who are our neighbours.”

“I know... that I’m disabled. I trust God because I’m doing things that I never thought I would do.”

A spirit of being

The stories of the disabled women were enriched by biblical parables and symbols they shared to compare their situations. Mama Lindiwe — one of the disabled women who have been involved since the story-telling workshop was initiated — formed the Abangani choir together with some of the other disabled women from her area. The choir sings at birthdays, weddings and funerals as well as any community events where they are invited to sing:

“I’m like that lamp. So I wish everybody could copy me. I see there is change even with the people I interact with.”

One disabled woman shared about the faith that many of them have in being able to provide for the basic needs of their children, by relating the biblical parable of the feeding of the five thousand in relation to meeting the basic needs with her family:

“The little I have becomes a lot”

The symbols and language used by the some of the disabled women and Community Rehabilitation Workers who are mothers of disabled children reflect the evangelical spirit they take into their work, “I must be like this light in the

community and preach about disability and how they can treat disabled people.”

A spirit of change

A significant change that has occurred since the start of the workshops was seen in disabled women now sitting down with family members, sharing and talking about issues related to their disability. In some instances the disabled women are getting other family members to help them with the small business.

One of the small groups of disabled women in a workshop felt that it needs to extend beyond the family, as the root cause of negative attitudes was a lack of awareness and information.

“Because others don’t know what disability is, they give us names. These things are destroying us. They call us witches and they say that a witch is dragging her feet...”

A spirit of compassion and hope

Many of the disabled women shared about their openness to help other people in their communities. Mama Rose, an elderly woman with an impaired right hand and leg following a stroke, was one of the disabled women who initially participated in the story-telling workshops. Since then she has been an active participant in the monthly workshops.

Conclusion

That these women have survived is a testimony to their resilience and inner strength and spirituality. The stories show how change needs to start with those who want the change, in this case the disabled women and their families. Pivotal to this is that disabled people should feel good about themselves and be sure of their own value as human beings. A healthy self-esteem has given them the power to begin changing their circumstances through a combination of practical action and advocacy.

Theresa Lorenzo is lecturing in CBR and disability studies at the University of Cape Town. She works with Zanempilo (formerly SACLA).

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XIV International AIDS Conference

The recently concluded AIDS conference in Barcelona with more than 15,000 participants from 194 countries has been amongst the largest conferences on AIDS and has driven up the stakes in the battle against HIV AIDS. It was difficult to differentiate from the pronouncements and statements of bureaucrats, technocrats, politicians and activists. This conference clearly put the onus on the political establishment of today. The challenge is obvious; the world today has been forced to take

notice of this horrendous pandemic which is sweeping across the world. The statistics are numbing. There is anger at the tardiness of the communities, governments and civil society in responding adequately. Churches and related organizations have the grave responsibility in contributing to this tardiness

There were various representatives of civil society and church related organizations at the conference in Barcelona. Their inputs were vital.

In addition, there were many technical presentations, poster exhibitions, addresses and panel discussions in which representatives from churches and related organizations actively took part.

The World Council of Churches in association with the Ecumenical Advocacy Alliance (EAA) organized a series of meetings for ecumenical partners in the evenings during the conference.

EAA compiled and distributed free of cost, a compact disc with a collection of resource material from churches around the world on the various aspects of HIV AIDS. These resources are now available in the EAA.

Website: www.e-alliance.ch.

The Future Role of Christian Health Care

In an effort to find out the problems of Christian hospitals in developing countries a consultation on 'The Future Role of Christian Health care' was conducted by the German Institute of Medical Mission in Tübingen (DIFAM) (supported by the Church Development Services - EED) at Tübingen, in March this year. The consultation, which was well attended by participants from more than seven countries and a dozen Christian organizations, focused on the sustainability of health care in Church related hospitals. In-depth case studies from Africa, India and Indonesia highlighted the challenges faced by Christian healthcare organizations working at grassroot settings in these developing countries. The group addressed some fundamental questions, which included: What kind of clinical



services was one talking about? What is the role of this kind of clinical service specially in developing a health care system? And whether sustainability and affordability were conflicting objectives? It also brought to the fore the complex obligations of Christian hospitals and underlined that there were no simple solution as no 'single rule' could be applied to all 'mission hospitals'. In addition it was felt that sometimes

donors responded too hastily and too abruptly.

Suggestions included the need for a new process of setting priorities in the church health system, the need for a new dialogue between theology, public health/medicine and economics and last but not least, the need for a new commitment to seek and do God's will. Participants also stressed the urgency to utilize resources judiciously, maintain a healthy mix of professionalism and evangelism besides looking for alternative options for 'user fees' and experimenting community based health financing.

Key speakers included Stephen Mutyaba, Sigit Wijayanta, Vijay Aruldas, Steffen Flessa, Eli Nangawe and Piu Tih Muffih.

THE ONLY LABEL THAT MATTERS IS LOVE

ROMANS 8:14

“For all who are moved (not labelled!) by the Spirit of God are sons and daughters of God”

Pim Kuipers explores the challenges faced by us as we work with community

It is so easy to label a person and we do it so often without thinking. Adjectives like disabled or even worse labels like ‘blind’, ‘dumb’ or ‘lame’ are tabs that we attach to people without thinking. Often it is a snap judgement, a prejudice based on transmitted custom or an image, we have in our minds. But people are not stereotypes. People are different, each a unique creation of God. And God recognizes us without our labels. He recognizes love, not labels. What is important is not the labels that are tied to our neck but the love in our lives. That is what identifies us and it is that which leads Him to call us His children.

Working with individuals usually fits well into our world view as we minister to people and have the opportunity to participate in individual restoration, healing or care.

Dealing with communities and social systems and structures however, reminds us a little too much of the ‘principalities’, ‘powers’ and ‘authorities’ that Paul warns we should be fighting.

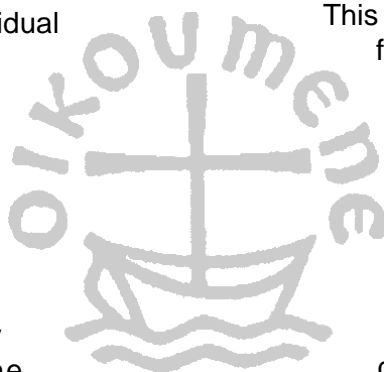
Moving the focus of our practice away from the individual towards the community or the society can be problematic. Not only is community-oriented practice difficult, but sometimes it is ethically and theologically challenging. Despite this, we are also reminded (again by the apostle Paul) that there is no authority except that which God has established (Rom 13:1). That goes for community and societal authorities and structures as well. We could say that God as creator has established our community and societal structures. Not only that, but recognizing God’s sovereignty, Christians see that there is a sense in which He operates through community and societal structures. Indeed we can see the evidence of his sustaining hand in communities and society in instances where they are truly ‘civil’.

As some scholars have pointed out, there is something about our common humanity, the ‘community’ we share, that reflects, however imperfectly, the image of God. It is important to remind ourselves that ‘God so loved the world that he gave His one and only Son’. The ‘world’ includes the community and societal structures. God gave his Son to redeem, not just individuals, but also the world. God’s creative and restorative activity is present in community and society as well as within individuals

So in one sense then, CBR and other community-based approaches are a way in which we as Christians can be ‘salt’ and ‘light’ to and through community structures and societal institutions.

This involves working with and fostering families and communities, it involves discerning the virtuous aspects of community life and harnessing them for the benefit of people with disabilities. It also involves engaging with societal institutions to ensure that they fulfil their obligations to people with disabilities. At times it will involve confronting exploitative aspects or practices within a community or society (confronting the principalities and powers).

- 1 Given that community and societal structures can also be understood as having been established by God, read Romans 8: 19-25 and substitute the word ‘community’ in place of creation.
2. Do you think that trying to positively influence communities through community-based approaches, is linked to liberating them from bondage and decay? What role might we have; what role does God have?
3. What place does ‘hope’ have in our efforts to work with communities to assist people with disabilities now, and in the future? (Rom 8: 24-25).



Web-sites related to Disability and Development:

www.disabilityworld.org/ This excellent web-site is dedicated to advancing an exchange of information and research about disability, development and disability rights issues. **Highly recommended!**

www.dpi.org/ This is the web-site of Disabled People International.

www.dag.virtualave.net/cbrforum.htm

www.healthlink.org.uk web-site of the former AHRTAG group. HealthLink has published for many years "CBR-News" later 'Disability Dialogue'. Some back issues can be found on their site.

www.hesperian.org/ The Hesperian Foundation is a non-profit organization committed to improving the health of people in poor communities throughout

the world by making health information accessible. It has some excellent publications on disability.

Web-sites related to Inclusive Education and CBR

www.eenet.org.uk Provides access to a unique and broad-based body of expertise and experience in the practice of inclusive education world wide. **Highly recommended!**

WCC PUBLICATIONS

So We Believe, So We Pray: Edited by Thomas F Best & Dagmar Heller
Worshipping and praying together have long been recognized as central to the quest for the visible unity of the church. This book treats such topics as worship as an expression and experience of common faith,

worship and culture, and local experiences of worship and unity in Latin America, Africa and India and in Orthodox and united congregations. ISBN: 2-8254-1159-0, 166pp, 1995, Price: Sfr 26.00, US \$ 15.95, 10.95 GB pounds, 17.00 Euro

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WHO PUBLICATIONS

A Focus on Women: by M K Gomel
Describes a series of practical initiatives for addressing the mental health needs of women and improving the treatment and prevention of common disorders. The document is an outgrowth of the new WHO Nations for Mental Health project, which

seeks to mobilize social, economic, and political support for combating the growing problems of mental disorders and substance abuse.

WHO/MSA/MNAM/97.4. 57pp. 1997. Price: Sfr 12. US\$ 10.80 in developing countries Sfr 8.40. Order no: 1930123

World Health Organization
1211 Geneva 27
Switzerland
Fax: 41 22 791 4167.
E-mail: austinm@who.ch

OTHER PUBLICATIONS

Helping Children Who Are Blind: Family and community support for children with vision problems — Sandy Niemann and Namita Jacob 200pp, US\$12.00 Children who are blind need extra help so they can learn how to use their other senses—hearing, touch, smell and taste — to explore, learn and interact with the world. The simple and engaging activities in this book, which is the first in the 7-book Early Assistance Series, will help those who care for children with vision problems. (The Spanish edition, **Ayudar a los niños ciegos** will be available in September 2002. Each book in the Early Assistance Series will include simple activities to help children under age 5 learn and grow well. The Hesperian Foundation is currently

developing the second book in the series, *Helping Children Who Are Deaf*).

Disabled Village Children: by David Werner
This book is meant for those concerned with community-based rehabilitation of disabled children. It provides clear, detailed information and easy-to-implement ideas for developing skills and how to make low-cost aids and the prevention of disabilities. The book contains a wealth of information for community groups, professionals and therapists, and includes information on polio, cerebral palsy, juvenile arthritis, blindness and deafness. Updated 1996, 654pp. US\$22.00.

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E-mail: bookorders@hesperian.org
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Tel: (from outside USA): 1-510-845-1447
Fax: 1-510-845-1445

ANNOUNCEMENTS

Thank you Nanda!



Nanda Chandrasekharan: 22 years of CONTACT history

On the occasion of the retirement of Nanda we would like to give her a **big thank you** for not only the longstanding, but also **outstanding role** she played for CONTACT.

Nanda joined the Christian Medical Commission in November 1980 at the time when Dame Nita Barrow was director. She subsequently worked under the directorships of Dr Stuart Kingma, Dr Eric Ram, and Dr Dan Kaseje. She worked with the following editorial assistants : Miriam Reidy, Ann Dozier, Sanda Freeman, Candace Jagel, and the following editors : Diana Smith, Darlena David and of course Reena Luke.

Her job has always been directly linked to the production of **Contact**, in all the various phases. : correspondence, maintenance of mailing lists for the various language editions, arranging for the translations, liaising with the printer, sending out the issues etc. She has always been a **wonderful team member**: supportive, considerate and modest, always willing to help and quietly efficient. With all her years of service she is very much our *Contact* and health work memory.

We sincerely wish Nanda many healthy and blessed years ahead in her retirement.

Christina de Vries (CONTACT Management) and Jenny Roske (WCC colleague).

Dear Editor

Thank you for Contact 174. We found it very informative and relevant to our needs in many aspects. Article 'Health Financing by the People' demonstrates how community-based insurance schemes can specifically benefit the rural and urban poor. It has been a great eye opener for us. We would definitely be interested to explore for the benefit of thousands of our clients who are served through our Community-Based Rehabilitation Programme. Please keep up the sterling work!

W N Ruvere, The Jairos Jiri Association for Rehabilitation of the Disabled and Blind, Bulawayo, Zimbabwe

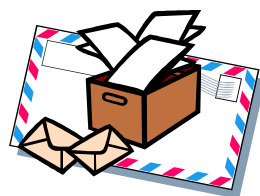
Dear Editor,

We are a government-registered society involved in rehabilitation programmes and we found Contact to be very informative and useful in our field of work. We would like to continue receiving this magazine and would be happy to send you our publication 'Disabilities and Impairment' to reciprocate your gesture.

Our activities include educating women for the early identification of the problems in their children, helping disabled people at different levels in their rehab programmes and facilitating programmes to help interaction.

Dr Roopa Vohra, Heritage of India Society, Delhi, India

LETTERS



Contact deals with various aspects of the churches' and community's involvement in health, and seeks to report topical, innovative and courageous approaches to the promotion of health and healing.

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Contact is also available on the World Council of Churches' website: <http://www.wcc-coe.org/wcc/news.contact.html>