

**GUEST EDITORIAL**

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**THE ORIGINS OF COMMUNITY-BASED REHABILITATION**

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**INTRODUCTION**

In 1973 Dr. Halfdan Mahler was elected Director-General of the World Health Organization. During 15 years he initiated a large number of new policies and programmes – a clear break with those that had governed WHO earlier. Dr Mahler was deeply concerned about “the existing gross inequality in the health status of the people particularly between developed and developing countries as well as within countries; this was seen as politically, socially and economically unacceptable”(1). There was also a reaction against the health sector concentration on high-level hospital care, which at that time consumed some 90% of the health budgets in most poor countries.

In the developing countries most populations, especially the rural poor had little or no access to any health care. As an example, visiting Cote d’Ivoire a few years later the author found three University hospitals in its capital Abidjan, each of them had more doctors than the entire population of some 10 million living outside the capital. The results of the lack of health care were devastating: high infant and child mortality rates, malnutrition, rampant epidemic diseases, chronic diseases, disability and low productivity. The indirect economic consequences were of great concern: workers produce better when they are healthy. The new WHO policy “Health For All” was to inspire all countries to deliver at least the essential services to all, making health accessible and affordable, while using appropriate technology.

The author was recruited to the WHO Headquarters in August 1974 as their first specialist in rehabilitation, the predecessors were from the public health sector, and rehabilitation had for them been a part-time job. Assigned to the Division of Strengthening of Health Services; a Division that had just started to develop the new health strategies, the author was given five months to produce a new disability /rehabilitation policy for WHO.

## **WHO POLICIES IN 1974**

The WHO existing policies had been guided by a group of eminent specialists, who had issued two Technical Reports, one in 1958 and the second and latest was from 1969(2). These reports contain policy recommendations and state-of-the-art technology descriptions and are distributed to all Ministries of Health. The citations that follow reflect the official view of the Organization.

The 1969 report states that "...rehabilitation is complex, involving several disciplines and different techniques working together as a team in order to achieve the best end results for the handicapped persons." It recommended that rehabilitation should "establish schools for allied health and rehabilitation personnel...to promote rehabilitation faculties of medicine should create chairs of rehabilitation medicine". A large part of their recommendations concern the setting up of medical rehabilitation centres – starting at the national level. Out-patients should be provided with transportation if they are unable to use public transport".

"The staff at the centre should consist of qualified specialists in rehabilitation medicine, nurses with additional training in rehabilitation, physiotherapists, occupational therapists, speech therapists and audiologists, clinical psychologists, prosthetists, orthotists, and social workers." The rehabilitation team was recommended to include: "vocational counsellors, placement officers, special educators and recreational therapists"; and "the following consultants must be available: orthopaedic, neurological and plastic surgeons, internists, psychiatrists, orthodontists; etc." The total (not including "etc.") comes to 20 different highly trained specialists. The Report gives some details of the content of the training for some of these specialists. It is to note that the Report states that the rehabilitation specialists "seem best qualified to deal with musculoskeletal dysfunctions. Other highly specialized fields /meaning: services for persons with blindness, deafness, mental disorders, developmental disabilities, mental retardation, leprosy and so on/ need to have their own services. Since rehabilitation is expensive, its costs must be borne by governments with the help and co-operation of social security agencies where these exist"

The final conclusion reads "WHO has an important part to play because the first stage of rehabilitation is purely medical, and further stages cannot be undertaken until the medical aspect has been dealt with. Nevertheless, any action taken to assist governments must

encompass the whole field of rehabilitation /meaning: only for persons with musculoskeletal disabilities/, from medical care to the resettlement of the individual in the society; each victim of a disabling disease or accident needs to be treated, rehabilitated, and reinstated in society the most favourable medical, social, educational and vocational procedure". The WHO report recommended that "rehabilitation should be established in developing countries", but expected "little or no action in these countries".

What is striking is that experts saw rehabilitation as very complex speciality dealing only with musculoskeletal disorders, needing very large resources, and to be based in high-cost national centres. Evidently, there would also be several other centres for the rehabilitation of persons with at least six types of disabilities.

The International Society for Rehabilitation of the Disabled (later renamed Rehabilitation International), with its main office in New York, had at this time as Secretary-General Mr. Norman Acton. The ISRD represented a large number of groups of the civil establishment different from the WHO experts: professionals, charitable service organisations and organisations of people with disabilities. In 1969, it organized a major meeting of ISRD experts in Killarney(3) to discuss what needed to be done in the underserved developing countries. The report stated that: "...it is obvious that the pace at which person-nel were being trained and other necessities for rehabilitation services were being developed was not adequate to meet the current problem and certainly incapable of coping with the predictable growth in the number of persons requiring professional help...it is possible that an objective analysis of methods of delivering rehabilitation services will suggest measures which can serve to provide at least the most essential assistance to large numbers of people with the resources available now or in the immediate future...experience in the less developed areas makes it clear that essential help may be given to disabled persons in ways which are often different from those methods established for use in industrialized and economically developed areas but are consistent with the available resources and the cultural, social, and educational patterns of the developing countries...it may be possible to identify forms and patterns of services which by requiring fewer trained personnel, less advanced levels of training, simple facilities, etc., may enable the delivery of essential services to be expedited and expanded."

Having reviewed the conventional system, the ISRD experts suggested in theory: a change of technology, a new service delivery system, and new types of personnel. They did not, however, propose any practical solutions. The underlying reason was that few of them wanted any changes. To find these was left to others, and it is easy to see why. A solution was being sought to a problem that had the appearance of being intractable. Altering it was seen as a threat to the comfortable traditional system. The only possible model for the WHO and ISRD experts was the “conventional” one, – with teams of professionals providing services in institutions and that the – in their eyes – firmly established system would not easily lend itself to any major changes.

In spite of the concerns raised at Killarney, most experts and organizations went on – and this was visible well into the 1980s – claiming that the only hope for future services in the developing countries lay in the extension of the existing pattern, essentially as described in the 1969 WHO Technical Report. Well knowing, – or perhaps ignorant – that there were insurmountable problems associated with this system; they had in reality concluded that providing rehabilitation in the developing countries was not feasible in our times.

### **ESTIMATION OF THE PREVALENCE OF DISABILITY**

An initial task related to the new WHO policy was to try to ‘count’ the prevalence of disability in a situation where there was no internationally recognised definition of ‘disability’ or of ‘disabled persons’(4). It was clear that cultural and developmental factors influenced the concept of disability, thus to find a consensus was not easy. One example from the developing countries was malnutrition: in 1974 at least 500 million were at that time affected and according the 2005 estimates by the UNDP 800 million people go hungry every day. Their functional capacity at home, at school (if they attended at all) and at work are clearly severely reduced: should they be included in the disability prevalence estimates? The author chose to include the people with the most severe forms of malnutrition. Disability is not always a yes/no situation (such as a fracture or an amputation), it is a quantitative problem. The grey zone is large: when an elderly person walks slowly at what point is this seen as a disability? How severe should mental disorders and pain be to count as disabling? When people have terminal diseases such as cancer, should they be included or not? If a disabling condition is cured

(such as tuberculosis, leprosy or depression) will we then drop this person from the prevalence account? There are certainly guidelines about some disabilities: such as blindness and deafness, and there are workman's compensation systems for assessing impairments in percentage points, when related to work accidents and diseases. Not until 2001, did WHO propose a system for disability classification (5). As the purpose of a WHO policy was to estimate the needs for rehabilitative health services, the proposal was that WHO should not try to do the impossible: making estimates of a health condition that will always be difficult to define, but rather make field studies to estimate the needs for services and actions (to promote their rights and quality of life, providing opportunities and inclusion) that could effectively reduce or eliminate the disabling consequences of a disease or trauma. While doing such studies one will recognize that for many disabling conditions (such as mental and neurological disorders) there may not be sufficiently effective and culturally appropriate rehabilitation technology, thus WHO needed to work with organizations and universities to encourage research.

In 1974, there were few national studies from developed countries to form the basis for the provisional assessment of disability prevalence and of service needs; 18 of these were located. All technical programmes at the WHO HQ provided the data they had access to. The provisionally estimated prevalence was about 390 million, or close to 10% of the world population (4 billion in 1974). The estimates of the largest groups causing disability were cautious: non-communicable somatic disease 100 million, malnutrition 100 million, hereditary disorders 80 million, accidents 75 million, communicable diseases 55 million, mental disorders 40 million, chronic alcoholism, and drug abuse 40 million. Later on, after years of observations of parental child maltreatment, the author would conclude that the disabling effects of childhood abuse and maltreatment – insufficiently known in 1974, and not included in the first prevalence estimates – were of major importance (6).

### **THE 1974 WHO POLICY DOCUMENT**

The conclusions of the draft policy document describing what in 1978 was named the “Community-based Rehabilitation Programme” (4), issued in December 1974 read:

“It might be pointed out that the principles for the programme development reviewed above will result in several major changes in the present approach. Among these are:

- (i) emphasis on properly planned services, which meet the priority needs of the population;
- (ii) to make services easily accessible and give sufficient coverage as many tasks as possible should be performed at the community level utilising simply, but sufficiently trained local manpower and locally available materials;
- (iii) expensive institutions, complicated equipment and dependency on highly trained professionals should be de-emphasised; when already in existence, such resources should be redirected to serve in the referral system that is necessary to provide supervision and continuous training for the community components.
- (iv) priority to the provision of technology directed towards quantitatively important problems that can be solved at favourable effectiveness/cost ratio, in response to the most pressing community needs”.

The draft policy document was during 1975 circulated at the WHO Headquarters for approval and then sent for review to the six WHO Regional Offices; there were no changes. In January 1976 it was adopted without any dissent by the Executive Board of WHO.

Written documents may contain the correct conclusions; to implement them in practice and to generate the stakeholders’ political will and support to accept major changes and total innovations would in this case prove to be a long-lasting test of creativity, diligence and endurance.

### **WHO’S NEW PROGRAMME FOR DISABILITY PREVENTION**

The data from the prevalence study – even if they were incomplete – indicated that about 50% of the health conditions causing disability could be prevented or cured: communicable diseases (such as poliomyelitis, measles, leprosy, tuberculosis, eye infections and syphilis), malnutrition (general calorie, vitamin and iodine deficiencies) and accidents. In the policy document issued in December 1974, it was proposed that WHO would promote, strengthen existing such programmes and initiate specific new programmes that could deliver the primary prevention and curative care in order to reduce the incidence of these diseases and their consequences.

During the following years WHO set up several new disability prevention programmes; blindness prevention, accident prevention, global immunization, deafness prevention. Existing

programmes, such as those for nutrition, maternal and child health and leprosy expanded. Global eradication programmes started for smallpox, leprosy and poliomyelitis.

## **WHO'S NEW PROGRAMME FOR COMMUNITY-BASED REHABILITATION**

The WHO CBR programme was developed in carefully researched steps.

### **Situation analysis**

A short inventory of the existing rehabilitation services in the developing countries was made and the conclusions were included in the 1974 policy document (4):

“rehabilitation services are practically non-existent or grossly inadequate in developing countries;

“there is an apparent lack of national planning and coordination of services (medical, educational, vocational, and social, etc.) in most countries;

“medical rehabilitation services have usually concentrated on institutional care, with a low turnover of patients at a high unit cost;

“when advanced rehabilitation services and technology have been introduced in developing countries, the result has often been discouraging or a complete failure.”

Further criticism would appear later on (6,7): those included the widely spread hidden abuse and severe neglect in residential institutions and schools set up for children with disabilities.

This was followed by a review of the future availability of personnel to carry out a programme for people with disabilities. In many African countries, de-colonisation had left a minimum of trained professionals. Nowhere was it worse than in Congo (Zaire) where in the 1959-60 academic year only 136 children completed secondary education and just 30 nationals were university graduates. There were no Congolese doctors, no secondary school teachers and no army officers; there were only three Congolese top ranking civil servants to administer a country with then some 20 million people and with a geographical area of 2,400,000 sq km. (60% of the combined areas of the 25 countries in the present European Union). Further analyses were made of other African, Latin American and Asian countries, and it became clear that it would not be possible to implement in these countries the system proposed in 1969.

In many Latin American countries social security systems financed rehabilitation hospitals, in principle servicing the insured 5%-10% of population. Many of the leading doctors had been trained at the Bellevue Hospital in New York and they tried to apply the US standards. In Asia some countries such as India, Indonesia, Sri Lanka, Republic of Korea, the Philippines and Myanmar had developed professional rehabilitation staff and national centres, but their capacities in comparison with the needs was nowhere more than symbolic. There were hundreds of small residential, day-centres and special schools for children with disabilities, with variable quality. Public rural services were virtually non-existent. The final estimate indicated 2% service provision in the developing countries. Poverty and underdevelopment were rampant everywhere.

The challenge was to find suitable practical solutions to close the gap – **a new entry point** – to implement the conclusions of the new WHO policy document.

### **Field studies**

#### Meetings at the central level

During the next three years a series of country visits were made to study the situation of disabled people in developing countries (7). The administrative responsibilities for services to persons with disabilities were mostly divided between several ministries, often with the Ministry of Social Affairs as the main focus. With few exceptions, health care staff had little knowledge and even fewer skills related to disability, it was not part of their regular training programmes. Health care systems, such as those for maternal and child care seldom dealt with disabled children. The segregation of disabled persons was often part of the culture: no mainstream services: no health care, no education, no jobs, and no economic support for the destitute. If provided at all, disabled persons had to attend segregated facilities. Disabled people were mostly seen as totally unproductive, dependent on others for their daily functions and subsistence, many were severely neglected.

When the author was received by ministers and colleagues they agreed that disability was a major health and social problem. They saw services as very costly, requiring large centres and expensive teams of personnel unavailable in the country. The therapeutic results had not impressed them. Furthermore, their budgets had no allocations for such services in the then present 5-year Plan and none had been proposed for the following Plan. If funds could be

provided, they would be happy to consider some project, but such external funds had to be secured for a very long time.

In many countries there were small organisations of parents and of persons with disabilities. In some countries they had approached the Social Affairs Ministry and with a lot of pressure received some small funds to economically assist their organizations and members. Rarely was there a national federation of these organizations; in some countries they were inspired to create one in order to give them more clout. These organisations rarely had rural members, although at that time some 85% of the populations were rural.

#### Learning from the people

After this mostly massive dose of discouragement at the central level the author turned to the periphery: rural villages and marginal urban areas, accompanied by a national who knew the local people and could translate and explain the situation, many of them were social workers. At each place, we met with the community leaders to discuss the prospects of community involvement, of finding local employment, of ways to let disabled people participate in informal job training. And then we would go to the school and find out if disabled children were there. The headmaster would explain his views of the problems. In some places we found empty schools; I was told that the teacher had a high absentee rate.

Then followed the home visits. During the preparatory years several hundred interviews were made followed by examinations of disabled people and their family members. Parents described how the disability started and what they thought had caused it. They related the problems they had experienced and what they had done to cope. It was common to find their explanations of the causes of the disabilities influenced by common beliefs. Most parents had gone to a local healer for advice and afterwards, if available, to the health service. Those consulted usually failed to propose anything useful, and told the parents that their case was “hopeless”. Most parents were looking for a ‘cure’ – some magic or medical procedure that would make the disability disappear. But most of them were willing to try some training at home to improve the functional situation of the disabled family member.

#### Detecting indigenous, spontaneous rehabilitation

Among these hundreds of villages and urban slum areas, there were examples of disabled

adults who had successfully trained themselves, and of disabled children whom family members had trained. Virtually none of these disabled people had any access to rehabilitation professionals. They had absolutely no knowledge of anatomy or physiology or diagnosis or assessment techniques or anything else that in the industrialised countries is thought to be indispensable procedures in rehabilitation. They had no commercially available equipment. Quite often they had produced technical aids or appliances themselves or with the help of a local craftsman. Some had managed to go to the local school and later found their way unassisted to a job or to self-employment.

A few examples (7)

**a)** The first example concerns a Middle East country, where poisoning with alkyl mercury leading to disability in an estimated 200,000 people: blindness, tunnel vision, ataxia, and paralysis.

Visiting rural villages in that country I found that the family members of those affected by the poisoning had rehabilitated many of the disabled individuals. Blind people had been trained in mobility and now walked about in their neighbourhoods by themselves, using canes. Children who had suffered paralysis had been trained successively to sit up, to move arms and legs, to stand up, to walk, to dress, to feed themselves, and many other activities.

Mothers – rural and without education – had played a key role in achieving results – results identical in quality to those one would have expected had professionals been involved.

**b)** A family in a small village in a Central American country had a 12-year-old boy who was severely hearing impaired. Herself barely literate, the grandmother explained that she had started taking care of the boy at an early age.

First, she took him to a local health centre. The doctor told her there was no cure. The only advice he had to offer was to try sending him to a specialised school for deaf children, far away from home. However, this school had a waiting list of several hundred children, and there was no way she could get the boy enrolled.

The grandmother, with no access to professional advice, started training the boy at home to communicate starting with simple home-invented sign language. With the help of a mirror, she taught him with some success to speak a few words. Some time later, she began training him

in lip-reading, and when he mastered that, she took him to the local school, where he did well.

The schoolteacher confirmed that the boy had always passed his examinations. The teacher then showed three children, all of them physically disabled, attending classes. Two of them were able to walk on crutches to school unassisted, while some older boys took the third one to school, in a small, homemade carriage. That boy also needed help to use the toilet.

c) In a poor African country, an organisation of disabled people had been set up. An energetic local leader with a serious disability had been chosen as president. With the help of local governors and village leaders, he managed to set up some dozen activities, providing schooling, jobs and an income for many of the organisations' members. All disabled children were sent to the local school. If they could not walk training equipment was produced locally (such as walking bars and crutches.) Some others were helped to get to school. Training for jobs included: cloth dyeing and sewing; shop-keeping; working in an agricultural co-operative; clerical jobs in the governor's and mayor's offices; community health worker, etc. All these disabled people received informal training/preparation, and the president used his personal contacts to find jobs.

Examples of these kinds of spontaneous and successful efforts were not numerous among disabled people in developing countries. But, a few hundred of them were identified. The dominating groups were children with mental retardation or with polio. It was encouraging to see that many of those parents who had been successful were willing to also help others in their community and train them in their techniques.

In some areas there was a very close co-operation with the local health centre; there were self-trained community workers effectively dealing with, for instance, contracture treatment for polio victims, correcting clubfeet, setting up walking bars and showing how to make simple crutches. The procedures were carefully noted down in detail. One important conclusion was that the spontaneous training was very similar in the countries visited in different parts of the world.

Self-training and home-training were not new concepts. They were frequently applied in many European countries. In most cases these were initiated by a physiotherapist or occupational therapist who during a few sessions showed the patient and/or a family member the home exercises. The patient was given a few sheets with written instructions (with

drawings showing the exercises to be carried out) of what to do at home and was then seen for follow-up evaluations, often spaced a month or so. This technique was also the preferred one for therapists who visited patients at home in rural areas and it worked well. Most such training programmes are simple and do not require extensive theoretical knowledge. The experience from the home-training of children with mental retardation and with cerebral palsy was especially positive; it not only had results that were equal to those by professionals, it also contributed to the bonding between the child and the parents (who provided the daily training) and reduced anxiety levels among the parents. Self-training did not produce second rate results.

The question was: could the effective type of “self-rehabilitation” in the community be used as a model for all? Could it substitute the Western technology? And, if so, how would we transfer the necessary skills and knowledge to all in need, how would we organize it, and how could we supervise the quality of results and finally how could such a programme be financed? How could a referral system be “constructed” to undertake the tasks that could not be managed by the community? Could poor people in the communities of the developing world be mobilized to help? It was necessary to first find out more about how community mobilization works.

### **Community Mobilisation**

Community mobilisation initiatives were studied beginning in the mid-1970s. In successful communities, there were good, educated leaders who had mobilized their people and moved out of poverty by “themselves”. There were rarely any international contributions to these communities (except for some initial training programmes and construction materials) and very limited Government economic support. Resources for development were mobilized locally. Programmes were studied in Argentina, Peru, Mexico, Guatemala, St Lucia, Benin, Mauritania, Chad, Côte d’Ivoire, Zimbabwe, India, Indonesia, the Republic of Korea, Thailand, Iran, Palestine, Nepal and the Philippines. Two descriptions follow.

a) In 1975, the author went to Indonesia for the first time and had opportunities to return there several times. An Indonesian organisation provided a study tour to several of their community projects in Java. In one such village, the community leader had for the last ten years mobilised the entire community in many projects. All men worked on Saturdays without

pay. The rich families, instead of working, provided money for the equipment and building materials. Other funds came from local taxes on land, harvests, buildings, weddings and so on; sixteen different taxes were raised and spent locally. The first of this village's projects was to build an irrigation system for their rice fields. When this was ready, there were three harvests a year, an important increase from the prior rate of one harvest per year. The increase of rice production gave jobs to everybody; it also increased the local taxes so that more projects could be financed: building latrines and eliminating the open street sewers that cause infectious diseases especially among children followed; collecting and disposing of garbage. Next, was a primary health care programme; three women were chosen and sent to a course. When they returned, they introduced immunisations, a maternal and child health programme, and a nutrition programme. At that time, malnutrition was rampant in Indonesia; it was the major child mortality cause. The village leader had needed just three months to eradicate malnutrition; he took the child register from his bookshelf to show the numbers. All newborn babies were regularly examined and weighed by the health workers, and when there were any signs of impaired growth, the family was visited. The health worker gave lessons at home in nutrition and supplementary foods; she showed how vegetables could be added to the polished rice that was the staple diet. Families started growing vegetables in their own backyards. These preventive health services were paid for by a small insurance fee raised from the entire population. It included a weekly visit by a doctor. Essential medications were dispensed at the health centre. Because the villagers deemed insufficient the education provided by the government, they built an additional school and hired their own teachers. The regular curriculum was improved by adding new subjects: health, how to cultivate additional foods (the school had a demonstration garden), set up fish dams, community work, and childcare. There was also a successful child-to-parent information component initiated by the school. The community leader made some reflections about his contacts with the authorities: they were informed about all projects, but did not sound happy. Although some were illegal or not officially approved, they did not interfere.

**b)** In Chad, a very poor Central African country, there is ongoing desertification. Access to clean, safe water is of great importance for the survival of the population. Ground water levels in the places visited were at 70 to 90 meters. Three international non-governmental organizations with expertise had arrived to assist; they had divided up the country in three

regions. National water technicians were trained to produce large rings of steel-enforced cement in wooden, re-usable moulds. The village people were taught to make first the wooden mould and then the rings. When the first ring was ready, it was put on the ground in a circular hole of the same size (diameter about three meters). Digging under the ring then started and went on until it was slightly under the ground level. When the first ring was down, another was put on its top, there was further digging; then the third ring was put in the top of the previous one, and so on, until the water level was found. To manage this project each village set up a water committee and the inhabitants who wanted to use the water assisted in the work. The NGOs provided the supervision by the national technicians, and donated the cement and the steel. The sand for the rings was paid by the community. When water was available, each family paid a small annual fee (a few dollars) for the maintenance of their well. Usually, the well was protected by a small roof and a fence to keep children and animals out, and was guarded to make sure that it remained uncontaminated. The author saw some 30 such wells during a week in the south of the country. Other community-based projects included the construction of storage houses for the crops, to decrease the large losses of grain eaten by rodents, maintenance of local roads, and construction of school buildings.

To sum up: community mobilization works, and was later on recognised by major international organisations as the paradigm. It was decided to use it as part of the strategy for CBR. It may be difficult in some populations to motivate people to offer their time to help others; this is sometimes seen in, for instance, in post-communist countries. With time, these problems diminish.

### **Sustainability**

The final analysis concerned the elements needed to needed make community-based programmes sustainable.

Three components of the sustainability concept were considered:

- technical sustainability: Does the programme have a technical manual that describes in detail the tasks to be done? Do those who implement the programme have this manual, and has it been translated to their local language? Are the local personnel sufficiently

trained to use this manual? Will a technical programme for the referral system be developed?

- cultural sustainability: Have the community members been given enough time to discuss and influence the decisions about a rehabilitation programme. Have all stakeholders been involved? Are there conflicts, which might influence the outcome of the CBR programme? What adjustments to the local culture are needed?
- financial sustainability: can the resource inputs foreseen for this programme be mobilized and then remain in place? If there is outside funding (e.g. from an international or national donor) can the long-term dependency on such funds be avoided, so that eventually only national resources will cover regular service delivery costs?

### **Conclusions from the Analyses**

Realising that the further preparation and testing of the proposed system would require several years, a detailed plan was produced in 1977 and presented it to the Director. The plan was for “Community-based rehabilitation” and it was greeted with enthusiasm by the WHO. The preparatory work started in 1978. The plan had several components:

- 1) Production of a technology manual (8) using indigenous technology to be field-tested. The manual would have several modules: a) Training Packages for community and family use, and b) Guides for the community personnel involved.
- 2) Development of the managerial components: a) survey techniques to identify persons with disabilities, b) planning, c) evaluation, d) organization of services including referrals, e) development of personnel, f) cost-effectiveness tools, and g) legislation,
- 3) Guides for a) the involvement of and empowerment of persons with disabilities, and b) strengthening of human rights, especially granting equal opportunities, access to public services (including those for economic support), facilities and institutions, and education to prevent abuse and neglect of persons with disabilities.

At this point several more important policy decisions were taken. “Conventional” rehabilitation had only aimed at persons with musculoskeletal disorders. Although in the developing countries these disorders were common among persons with disabilities it was decided to include all other major groups, examples are: persons with a) seeing, b) hearing, c) speech, d) moving, e) learning difficulties, and persons with f) epilepsy, g) mental disorder and h) leprosy. It was

inconceivable to create separate community programmes for each of these, and there were many examples of persons with multiple disabilities. Some competence for these eight “sub-specialities” could be available at the first referral level; further specialisation could be provided at higher levels. At the same time, WHO initiated the concept of the multi-purpose health worker along these same lines. Directly connected to this change was the policy decision to include in all community-based rehabilitation projects all aspects, not just the health sector, but also seeking full co-ordination with education, skills training, income generation, social services and human rights (9).

The next policy decision was yet another break with the conventional system. This had (in accordance with the 1969 WHO recommendations) usually started with the setting up of a “national centre”, in the belief that later on this centre would develop ramifications and decentralized services. In reality this had rarely been the case. National centres stayed national centres, and more often than not they turned into ivory towers. Now, the entry point was moved to the community.

In this spirit, the CBR system proposed to start all service development from below, first encouraging the establishment of community services and, at a later stage, linking them to a referral system. The referral system should be created once the community needs were known, preferably after a sufficient period of implementation. In a system built from below, the educational objectives for professional staff working at referral centres will be formulated in response to local needs while taking into consideration how existing resources could be restructured and decentralized. At its inception, a CBR system would be simple. Over time it should be upgraded from below, by improving community workers’ competence through in-service training programmes. Family members who act as trainers of disabled individuals will develop their abilities through guidance and experience. Local schoolteachers could learn more about how to integrate disabled children, possibly with the assistance of a mobile resource teacher. Community leaders could start projects for integrated, informal ability training and help disabled people to an income-generating activity. Communities would provide economic safety nets for those without any means for survival. Human rights could be better protected; and disabled people and parents should obtain more say and better representation of their views.

The term ‘community-based’ contained yet another new policy. The decision to implement a local programme would be made in a decentralised system, where communities would decide if the programme had a priority interest to them. Their decision would not be influenced by pressure from above or from the outside. Communities that showed interest would have to agree to provide some local resources themselves, mainly for a community worker (7).

The policy changes were significant and their implementation required many basic changes. CBR was a realistic, common sense system facilitating primary rehabilitation to be set up in poor countries. It was simple, and could be maintained using local resources available in all countries. CBR was the first programme in WHO to describe it as community-based; it proposed a new entry point. From that entry point each country would develop their future systems based on needs assessments, the availability of local and national resources, the views of the stakeholders and adapting it to the local culture.

#### **REHABILITATION AS A COMPONENT OF PRIMARY HEALTH CARE**

By the end of 1978, the WHO and UNICEF conference on “Primary Health Care” was held in Alma-Ata with participation of health officials and many non-governmental organizations from all countries in the world. This Conference had a major influence on the standing of rehabilitation. The final Declaration included these statements:

“Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country’s health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.”

“Primary health care:

- Reflects and evolves from the economic conditions and sociocultural and political characteristics of the country and its communities and the application of the relevant

- results of social, biomedical and health services research and public health experience;
- Addresses the main health problems in the community, providing promotive, preventive, curative and rehabilitative services accordingly;
  - Requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate;
  - Should be sustained by integrated, functional and mutually supportive referral systems, leading to the progressive improvement of comprehensive health care for all, and giving priority to those most in need.”

In 1978, an agreement was negotiated at the UNICEF Headquarters in New York with its Deputy Administrator. UNICEF would be a partner in the CBR programmes; this was natural as the priority would be children. The UNICEF recommendation was published in their newsletter, but soon afterwards UNICEF got a new Administrator who made major changes in the agency’s activities, which then became centred around immunization and anti-diarrhoea programmes.

### **FORMULATING AND TESTING THE TECHNOLOGY**

In full agreement with the proposed major policy changes, WHO in 1979 provided a budget for the CBR implementation. Two very competent consultants were recruited to assist with the preparation of the CBR technology: Ms. Gunnel Nelson from Sweden and Mrs Padmani Mendis from Sri Lanka, who remained with the CBR programme for many years.

The first experimental Manual “Training in the community for people with disabilities” was completed by the end of August 1979. It had about 1,100 pages and 2,000 provisional drawings (8). There were

- a) 20 training packages for the family,
- b) four Guides for the community worker (called local supervisor), the school teachers, the community leaders and one with advice for how persons with disabilities could set up a local organization to promote their own views and,

- c) an introductory chapter with managerial proposals, describing the principles and policies, and how to plan for, manage and evaluate the programme. In October 1979, a meeting was held in Mexico City to discuss the testing of the Manual with interested partners from nine countries.

By the summer of 1980, we were ready for the first revision based on the field tests. Among the first countries were Botswana, Pakistan, Mexico, India, Burma, Nigeria and St Lucia. The number of test countries increased, for the newcomers a 3-week preparatory course was held in St Lucia in 1982. In 1983, we held a meeting in Colombo to discuss the test results with a very large group; the second revision was produced during that year, it was extensive and took five working months. That version was printed in a few hundred copies by WHO and distributed. Soon after came the first translations: Burmese, French, Malayalam, Singhalese, Somali, Tetswana, and Urdu. The field testing continued until 1987, it included revision of the evaluation programme, a review of the effects of the referral systems, and visits to ten countries that had requested assistance with their national planning. Several regional seminars were held to explain the principles and implementation of CBR. University Departments for Tropical Medicine, among them London, Liverpool and Uppsala started courses in CBR.

The final revision was made in 1987. It built on the feedback we had got from hundreds of people who had taken part in the field testing. Some training packages were added. As many of the users were semiliterate, it was mandatory to simplify the text. A special computer programme was set up to streamline the language (reducing the number of different words to 1,400; using only basic English; shortening the length of sentences.) Besides the changes facilitated by the computer analysis, great efforts were made to write all texts in a very simple manner. Sentences were short, direct and had no double negatives. For clarity's sake, the text was somewhat repetitious. Each word carried only one meaning (e.g. the word "right" is used to signify exclusively the opposite of "left"; the opposite of "wrong" is "correct").

All 2,200 drawings were changed to line drawings and re-created by an artist. The technique for making drawings was based on a literature review of the use of illustrations in manuals and other publications for developing countries. It appeared that, apart from photos, line drawings alongside the text are the easiest to understand. The drawings were field-tested and adapted accordingly. They were made in such a way that local details such as dresses,

hairstyles, houses, and so on, would be easy to change to make them fit the actual environment.

At this point, the various parts of the Manual were sent to twenty peer reviewers. We then incorporated their changes – they were rather few – in the text. The text was delivered for printing in 1987; to print it took two years until 1989. In spite of repeated protests, the book was a luxury product, with many colours and very expensive. Few people in developing countries could afford to buy it, so WHO had to give it away. Most countries just acquired one Manual, and then photocopied it. Many local translations were made, at present 55 of these have been reported.

### **WHO ADOPTS THE NEW POLICY**

In 1981 an Expert Committee meeting was held at the Geneva Headquarters to issue a new Technical Report Series publication (10). It coincided with The United Nations International Year for Disabled Persons (IYDP). Experts from all the six WHO Regions participated together with staff and representatives from the United Nations, UNICEF, UNDP, ILO, UNESCO, the Council of the World Organisations interested in the Handicapped (a joint organisation of all major non-governmental organizations, including of persons with disabilities and parents), and the International Social Security Organization; totally 23 experts.

The Expert Committee did not produce any definitions of the terms: impairment, disability and handicap, as these terms were under review by the Tenth Revision Conference of the International Classification of Diseases (ICD), the finally proposed system did not appear until 2001 (5). Terms used reflect the 1981 usage.

Discussions focused on the situation in the developing countries. Among others these facts were recorded: “mortality among children is much greater than among unimpaired children. Morbidity is also higher. Disabled adults have lower incomes, and are more likely to suffer from poverty. Visibly disabled adult women are often abandoned by their husband and deprived of their children. Disabled children have fewer opportunities to attend school. They seldom get vocational training and are often un-employed. Few of them marry and found a family. The presence of one child with visible and stigmatizing disabilities in a family has negative consequences for the marriage of the brothers and sisters. Social segregation is widely spread because of deep-rooted fears and beliefs, originating from age-old cultural and religious convictions – for instance that the disabled are possessed or under divine

punishment. The disabled are very often excluded from any position of leadership in their communities and in general excluded from planning and decision-making in their societies. Their complete lack of representation in community affairs results in the neglect of their needs.”

The Committee adopted some definitions: “Rehabilitation includes all measures aimed at reducing the impact of disabling and handicapping conditions and at enabling the disabled and handicapped to achieve social integration. Rehabilitation aims not only at training disabled and handicapped persons to adapt to their environment, but also at intervening in their immediate environment and society as a whole in order to facilitate their social integration. The disabled and handicapped themselves, their families and their communities they live in should be involved in the planning and implementation of services related to rehabilitation.”

“Community-based rehabilitation involves measures taken at the community level to use and build on the resources of the community, including the impaired, disabled and handicapped persons themselves, their families and their community as a whole. Social integration is viewed as the active participation of disabled and handicapped persons in the mainstream of community life. In order to achieve this aim it is necessary to provide adequate rehabilitation for all the disabled and handicapped and to reduce to a minimum all handicapping conditions in all aspects of their environment.”

The Committee recommended the following strategies and approaches:

- (1) “prevention of disability through all types of measure within and without the health sector”
- (2) “community-based rehabilitation with the aim of total coverage of all populations”. In view of the high costs of institution-based rehabilitation the Committee recommended “that it should be explained to the public that if a shift is made from institutional care to community-based rehabilitation, and if the relatives of the disabled undertake to look after their disabled family members, equally good, if not better care, can be provided at much lower costs to society as a whole...there is much evidence to suggest that the training of the disabled in self-care and provision of therapy at home by family members or other lay persons supervised by professionals give similar or better psychological than training directly by a professional in an institution.”

The Committee emphasised the importance of early implementation; stating that it “will be necessary to restructure and re-orient the present organization”, especially by “strengthening community services”.

The Committee referred to previous reports (11,12) that had showed the serious economic consequences of delaying or taking no action to promote rehabilitation.

The policy of community-based rehabilitation has been supported by several resolutions taken by succeeding World Health Assemblies (the WHO body constituted by Representatives of all the Health Ministries of all the Member States).

### **DEVELOPMENT OF MANAGERIAL TOOLS**

The development of the managerial tools was built on the experience from country visits. Already in 1975, there were requests from many developing countries for service and personnel planning. A number of early regional and country seminars were held with representation from the Government, professionals, service providers and representatives for organisations of disabled persons and of parents. It became evident that structured courses in management were needed, few of those who attended had ever made national plans, formulated objectives, generated alternative solutions to problems and calculated and compared their cost-effectiveness, discussed how to analyze population needs and design curricula content based on such needs. It was common to copy such components from the developed countries, with little adaptation.

Eventually, organised courses were held for some 400 persons from over 100 countries, many of these in the 1990s. From 1992 and onwards, the books and documents were produced by the United Nations Development Programme (UNDP) and distributed to all course participants (7, 13-19).

### **FINANCING CBR**

The WHO’s programme budget is divided between HQ and six regional offices. During the first few years the Programme for Disability Prevention and Rehabilitation (its first name) had no budget of its own. The Division Director, Dr. Kenneth Newell during the early development of the CBR allocated funds using an account from Swedish Sida. A few years after, an annual amount of just US\$ 20,000 from the WHO regular HQ budget was allocated

for the external activities of its Rehabilitation programme (above this the WHO/HQ budget financed the personnel – one professional and one secretary – and the office costs). This was unchanged for many years. As this was insufficient for the development of a new programme, outside funds had to be raised for the activities – such as the production of the technical Manual and the field projects. In 1982, Sida started to provide funds for the programme directly and regularly, the annual amounts were about US\$ 300,000.

The Sida funds were used for the production and testing of the manual, and for assistance to the setting up of country programmes: planning, courses for the personnel, providing manuals and translations, evaluations, and support to research projects. Although now several doctoral theses have been published – more encouragement should be given to the nationals from the developing countries. CBR is a strategy, not a programme just to be copied; it needs to be adapted into the local culture and social conditions (16). Research is fundamental; the starting point can be the existing evaluation tools (15,18).

A number of non-governmental organizations joined WHO, and financed programmes in several countries, in the 1980s among them DANIDA, NORAD, Norwegian Red Cross, Save the Children, French National Committee for the Disabled, and French Handicap International.

The principle for financing of CBR was that public funds should be available. Dependency on charitable funds should be avoided, these could at best be supplementary.

### **DEALING WITH THE RESISTANCE**

It would be natural to expect that the stakeholders in the ‘traditional’ system would for various reasons resist the policy changes adopted and promoted by WHO, and by other UN Agencies.

#### The battle about residential institutions

For a very long time services for persons with disabilities had been carried out in residential institutions. Such institutions are comparatively easy to set up and manage, and to raise money for, as the organisations can show photos of the institutions and of the children. Some of them have schools. But there are also State-managed “orphanages”, places for mostly healthy and some disabled children abandoned by their mothers; the main reason being poverty

(6). Many of these were just 'storage' places; the children were neglected and maltreated. International, charitable organizations had set up hundreds of these in developing countries; many could be found in places like Nicaragua, Palestine, Egypt, Kenya, Zimbabwe and Bangladesh; and a few in Mauritania, Chad, Somalia and Honduras. Organisations of blind people had set up special schools in many countries and there were some for deaf children. Some mentally retarded children could be found in orphanages. Most such institutions are closed to visitors, hiding abuse and violence behind the facades. The author has been refused entry to some of them. In the beginning, the institutions shown were "the best ones" and well prepared (sometimes newly painted) for the advertised visit. It took some time to get to know the extent of "cruel, inhuman and degrading treatment" taking place in many "homes" (6).

In many developed countries the closing of residential institutions started in the 1970s, transferring children to families or substitute families. The reasons were clear: the abuse and neglect destroyed thousands of lives. The children would stay in families which received increased assistance with day-centres, personal assistants, transportation, adaptations of their homes and grants. Resources for inclusion into the mainstream: social activities, schools, vocational training and jobs were vastly augmented. Civil organisations of persons with disabilities and of their families were supported and given real political influence.

The WHO CBR programme proposed alternatives to residential care: among them day-care, support to families, social and economic safety nets for adults, home and referral services and inclusive solutions using mainstream educational, training, employment programmes and human rights support (7,8,17). Those, who were engaged in residential homes, were not pleased: the truth was unwelcome and inconvenient.

#### The battle with professional groups

When the CBR policies were developing, there were many contacts with professional organisations. Some of them were very interested and willing to adapt, but most were not. That training of disabled persons in daily life activities was to be made by family members (lay persons) made some of them feel that they as professionals were going to be redundant, lose their jobs and income. They seemed to have forgotten that home-training and self-training were already accepted components of their daily job. It was from the beginning evident that a programme based in the community would not be able to provide all services

needed. Referral services should be set up; some of them already existed in many countries. An expansion was foreseen; thus there would be more, not less jobs for the professionals.

When the experimental Manual was published in 1983, an anti-CBR campaign started. A large number of articles were sent around to hundreds of people to create a hostile reception of CBR. These implied, among other things that: CBR had been invented in the Ivory Towers of Geneva, by people who had never bothered to go out and look at the realities, that it was gigantic misplanning by incompetent persons, and even that we had personally bribed the people in the test countries to make them report positive results. Gradually, the resistance from the professional groups subsided and was replaced by acceptance.

#### The battle with the International Monetary Fund (IMF) and the World Bank (WB)

While trying to implement the community-based rehabilitation programme, which was supported by all technical UN agencies, there was opposition from the IMF/WB country staffs. The resistance to 'social' programmes was obvious during the 1980s and 1990s. The ongoing IMF/WB economical structural reform programmes made it impossible for Governments controlled by them to employ even a single person to start social programmes; and such programmes as existed were often cut down. The WHO- and UNDP-sponsored CBR programmes were low-cost projects for the poorest of the poor, who had no social safety nets. Lacking help to improve the functioning of their disabled children, many poor saw their children meet an early death. High institutionalisation costs for such children could have been avoided had there been a CBR programme in place to transfer training skills to the families and the community.

In 2002, the United Nations Institute for Social Development (UNRISD) in a publication reviewed the social policies of the WB and IMF during the 1980s and 1990s. It states that these Organizations "prided themselves in not wasting their time on 'soft' things like social policy in designing their 'structural adjustment programmes... Diverting resources to social policy, which softens the blow of adjustment on the weaker sections of the society was regarded as a way to slow down the necessary adjustments... This was pursued to the point of producing a call for 'adjustment with human face... by those who were deeply concerned by what they saw as unnecessary human suffering caused by such programmes in their unadulterated forms" (20).

The battle against paternalistic attitudes and the introduction of democratic influence

Many persons with disabilities are powerless. Parents, neighbours, caregivers at day centres and in institutions give them orders, never listen to them, forbid them to go out, to have their own friends, go to the mainstream school, get married, have jobs, and so on. The straitjackets are always there; if not physical then they are emotional and social. Adults with a disability are treated like children, they are told what to do, when and where. They are dominated by people with paternalistic attitudes. In the CBR Manual, we introduced a Guide with some ideas about how a local association of disabled people and of parents could be established. It is important that people with disabilities are empowered to take care of their own affairs.

The battle against “false CBRs”

By the late 1980s many donor organizations had heard about CBR and it became easier to get funding if programmes for disabled people were “community-based.” There appeared suddenly hundreds of “CBR projects”; in reality the “traditional” ones just changed their names, without bothering to apply any CBR principles. For example, a residential deaf school that had been there for 30 years, (surrounded by barbed wire, to prevent anybody from visiting it) suddenly got the name of CBR. New residential institutions were built, and segregated schools set up, now with the new name. Other initiatives were “interesting”: a Professor at a University Rehabilitation Department got a large grant “to introduce CBR in a village”. The activities – which went on for three years – consisted of sending out the Department’s professional personnel to give lectures about what they were doing at the hospital. No person in that village was examined, no local programme was offered. It proved very difficult to have the programme evaluated (and as a result closed down), as the initiator meanwhile had become Minister of Health.

When the managers of such enterprises were informed about the “proper CBR” it generated a lot of heat.

**CBR IN THE DEVELOPED COUNTRIES**

In the 1990s several developed countries started to introduce CBR strategies, among them the Scandinavian countries and in many in Central and Eastern Europe. Institutional services were changed into family support, using day-centres and inclusive education. The

management is carried out by a community committee which receives local financing. A successful programme has been set up through community-based initiatives in Portugal. Parents of disabled children initiated support services, such as day-centres. Over the last 25 years the system has expanded to cover the entire country. Through local boards hundreds of community members are directly managing the local services; they have many active volunteers, among them groups of high school children. Eventually they succeeded in receiving about 80% financial support from the Government. CBR is not just a programme for the poor developing countries, its principles can be adapted to even the most developed ones: engaging the community will help to change psychological atmosphere, break the isolation for the excluded, increasing opportunities and making their human rights a reality; in short for persons with disabilities recognition of their dignity replacing the customary prejudice.

### **CHILDHOOD VIOLENCE AND MALTREATMENT**

Already early during field visits the author observed widespread child abuse and neglect. The first were among disabled children living with their birth parents. At examinations, there were marks of beatings, sometimes there were fractures which could only have been caused by an adult. Children with moderate mental retardation, cerebral palsy or blindness were found who had during their entire life been locked up alone in a room, never seen or known by any neighbour. Many disabled children are malnourished, for some of those the damage had been intentional. In Botswana, a country which then had a population of 800,000, half of them under the age of 18, there were found just a handful of children with cerebral palsy, and not a single adult with this type of disability. There should have been at least 800 of them, but they had not survived.

In 1983, the Government of Nepal carried out a disability survey. It showed that the prevalence of disability among boys was double that of girls. Most disability was caused by polio, which affects boys and girls equally. In all groups of different types of disability the results indicate a higher prevalence of disabilities among males compared to females. The explanation was that the disabled girls met an early death more than the disabled boys did. The cause of death was most often quoted as pneumonia or diarrhoea, but in reality it was family neglect. A survey carried out in India in 1997 showed similar results (6).

To sum up, after a review of the scientific publications it became evident that about fifty percent of all persons with disabilities are victims of sexual, physical and /or emotional abuse. Most of this takes place while they still are children. Most perpetrators are parents and other care-givers. These studies have been enlarged and appear in a separate book (6). It is clear that the CBR programme cannot disregard this important problem.

### **MEDIA**

During the CBR development period, a large number of lectures were given and many articles written to explain the strategy behind the changes. One of the first was in 1979 at the Royal Society of Physicians in London, the ideas were well received and the lecture published<sup>21</sup>. Many organisations came to Geneva for information. In each country visited there was often a seminar covered by television or radio programmes.

CBR has been presented to both to small groups and to large meetings and conferences, over the years attended by a total of over 10,000 persons. These have served to explain the reasons for the policy changes adopted by the WHO, and the necessity to adapt the strategy to the local culture. They also served to increase the awareness of the lack of application of basic human rights to persons with disabilities, and the large-scale sexual, physical and emotional abuse that victimizes many of them.

### **THE FUTURE OF CBR**

CBR was based on a thorough study of the living conditions and of the abilities and needs among persons with disabilities in the developing countries. CBR is a strategy defining a new entry point. Action to improve the quality of life of disabled persons would no longer be based in highly specialised institutions away from the mainstream; it would be available next to those who needed them. Community mobilisation was identified as important. Changing the entry point also implied very thorough changes in the entire traditional system, including existing policies; supporting the empowerment of persons with disabilities and their organizations, providing better opportunities, and promoting their human rights. Using that entry point, each country should develop its own culturally adapted policies, plans, actions and services in a future system based on needs assessments, the availability of local and national resources, and the views of the stakeholders. During the last years, many new partners, among these

many who have attended the management courses and, members of the Disabled Peoples Organizations (DPOs) that have emerged during the last decades have joined the efforts to further develop the CBR. ILO, UNESCO and WHO, the main United Nations agencies, have issued new publications in support of CBR. After over 30 years the strategy remains in the focus. A major support group has recently after four years of work produced a CBR manual with detailed guidelines, based on the accumulated experience.

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## **He's my Brother! She's my Sister!**

### **The Role of Siblings in Special Education**

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