

Equal Opportunities for All: Promoting Community-Based Rehabilitation (CBR) among Urban Poor Populations

Initiating and Sustaining CBR in Urban Slums and Low-Income Groups



Forword

The WHO Disability and Rehabilitation (WHO/DAR) Team and the Italian Association Amici di Raoul Follereau (AIFO) are happy to present this document entitled *Equal Opportunities for All: Promoting Community-Based Rehabilitation (CBR) among Urban Poor Populations*.

Over the last 20 years, WHO has gained considerable experience in developing and implementing CBR with and for persons with disabilities. However, most of the experience of CBR has derived from rural areas in developing countries. At the same time, we are keenly aware that even in large metropolitan cities specific population groups, such as persons living in slums and in low-income areas in urban peripheries, may also face difficulties in accessing the available rehabilitation services.

For this reason, representatives of organizations working in urban slum and low-income areas were invited to a consultation in Manila (Philippines) in September 1995. As a result of this consultation, basic guidelines on implementing CBR in urban slum and low-income areas were prepared.

The strategies defined in Manila in 1995 were implemented through a joint collaboration between WHO/DAR and AIFO from 1996 until 2001, whereby pilot projects in various parts of the world were set up. During this period, the centres participating in the initiative visited each other and met periodically to reflect on their experiences, and to share ideas and information about their successes and constraints.

In October 2001, representatives of the pilot projects assembled in Bologna (Italy) for a final meeting and to prepare a report on the implementation of CBR in urban slum and low-income areas. This report also presents glimpses of the journey made by the participants of the initiative — in discovering and learning about each other's work.

As a result of these projects a guide for Rehabilitation in Primary Health Care entitled *Promoting Independence of People with Disabilities due to Mental Disorders* was published in collaboration with the Mental Disorders Control Unit, Division of Mental Health and Prevention of Substance Abuse, and the WHO Regional Office for South-East Asia. The Division of Mental Health and Prevention of Substance Abuse also provided training for people in urban slums in Kenya.

We should like to thank all persons from the slum and low-income communities and the organizations working there for giving their time and energy to this initiative, and for making it a success. Thanks are also extended to DAR donors and, in particular, the governments of Italy, Norway and Sweden as well as institutions and individuals who have provided support.

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Cover photograph: *Participants of the "CBR among urban poor populations" initiative during the final meeting on a visit to the Disability Documentation Centre, Bologna, Italy, 24 October 2001*

Table of Contents

Background.....	4
<i>General.....</i>	4
<i>CBR in urban poor communities and slums</i>	4
<i>Projects participating in the initiative.....</i>	5
<i>Methodology of the pilot case studies in the field projects.....</i>	5
Strategies for Implementing CBR in Urban Poor Communities and Slums	6
<i>The urban poor and slum dwellers</i>	6
<i>Initiating CBR</i>	7
<i>Understanding the needs</i>	8
<i>Empowerment and community participation.....</i>	8
<i>Promoting DPOs</i>	8
<i>CBR and community committees</i>	9
<i>Role of public authorities</i>	9
<i>Role of CBR personnel</i>	9
<i>Role of community volunteers</i>	9
<i>Activities</i>	9
<i>CBR resource centres</i>	10
<i>Creating links with other existing programmes</i>	10
<i>Monitoring and evaluation.....</i>	11
<i>Conclusions</i>	11
The Process.....	12
<i>The consultation in Manila (Philippines) in 1995.....</i>	12
<i>After the Manila meeting.....</i>	13
<i>Agreement between WHO/DAR and AIFO.....</i>	13
<i>Additional pilot projects.....</i>	13
<i>Sharing of experiences and learning from each other</i>	14
Annex 1. Participants at the Final Meeting	15
Annex 2. Agenda of the Final Meeting.....	16
Annex 3. The Final Meeting in Pictures	17
Annex 4. Extracts from the <i>Sharing</i> Newsletter.....	19

Background

General

At a global level, 7–10% of the population is estimated to be disabled. A large number of disabled persons, especially in the developing world, have no access to institutional rehabilitation services that are usually based in big cities with a limited service capacity.

The concept of community-based rehabilitation (CBR) was proposed by the World Health Organization (WHO) in the late 1970s to increase the coverage of rehabilitation services for disabled persons. Initially it focused on medical and functional aspects of rehabilitation needs. Soon afterwards other agencies of the United Nations, United Nations Organization for Educational, Scientific and Cultural Development (UNESCO) and International Labour Organization (ILO) proposed similar approaches for dealing with the educational and occupational aspects of rehabilitation. Implementations of field activities based on this approach, which values existing resources, skills and capacities in the families and communities, were known as the “WHO Model”, “UNESCO Model” and “ILO Model” of CBR.

Gradually it became clear that, for CBR to be effective, disabled persons require a multisectoral approach that covers all aspects of life. It was also evident that these activities related to medical, social, psychological, educational and occupational aspects have limited impact on the lives of persons with disabilities and their families unless attitudes change in the communities, unless there are effective national policies and laws which guarantee equal opportunities to all citizens, and unless persons with disability themselves have the possibility of making choices and are empowered to take decisions concerning their own lives.

This evolution in the concept of CBR resulted in a collaboration involving WHO, UNESCO and ILO in 1994. A paper entitled *Joint Position Paper on CBR* ensued, which attempted to go beyond the different “models”. It defines CBR as:

...a strategy within general community development for rehabilitation, equalisation of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services.

The present document, *Equal Opportunities for All: Promoting Community-Based Rehabilitation (CBR) among Urban Poor Populations*, proposes general guidelines for initiating and sustaining the CBR approach in urban slum and low-income areas. The document is based on experience of working in urban slum and low-income areas in several countries.

CBR in urban poor communities and slums

In the last two decades, efforts for promoting and implementing CBR programmes have concentrated mainly on rural areas. At the same time, it has been recognized that disabled persons living in slums and low-income areas in urban settings do not have full access to the existing rehabilitation services. Keeping this in mind, in September 1995 the Rehabilitation Unit of WHO, which is now named the Disability and Rehabilitation (DAR) Team, organized an international consultation in Manila (Philippines) on the feasibility of implementing CBR in urban poor communities and slums.

Representatives of ten organizations involved in community development activities in urban poor communities and slums were invited to this consultation. The participants agreed that integration of the CBR approach into their existing activities was feasible if the activities were targeted at specific vulnerable groups, including persons with impairments, street children, single mothers, drug and

substance abusers, etc. As a result of the consultation, a report was prepared entitled *Equal Opportunities for All: A Community Rehabilitation Project for Slums*.

Based on this document, the ten organizations were invited to elaborate proposals for projects, which could be submitted to the WHO/DAR for support. It was decided that these projects would be used as pilot case studies to verify the applicability of the ideas discussed in Manila to field conditions and that, after a limited period, the project implementers would be invited to meet for a second consultation in order to review and finalize a strategic document on initiating and sustaining the CBR approach in urban slum and low-income populations.

Projects participating in the initiative

Five of the ten organizations that participated in the Manila consultation in 1995 presented a project proposal, which was approved by WHO/DAR, and support was provided to initiate these pilot case studies. An Italian Association Amici di Raoul Follereau (AIFO), which was already collaborating with WHO/DAR for implementation of CBR programmes, became a partner of WHO/DAR so that the projects could be followed, monitored and facilitated.

Three additional projects not deriving from the Manila consultation joined the initiative at a later stage. Thus, a total of eight projects have participated in this initiative and are located in the following cities:

1. Alexandria, Egypt
2. La Paz, Bolivia
3. Makassar (Ujung Pandang), South Sulawesi, Indonesia
4. Mumbai, Maharashtra, India
5. Nairobi, Kenya
6. Quezon City, Philippines
7. Salvador, Bahia, Brazil
8. Santarem, Para, Brazil

Among these eight projects, two (Egypt and Indonesia) have direct governmental involvement through personnel working for ministries of health, while the others are supported and managed by national nongovernmental organizations (NGOs) and grass-roots organizations (GROs), though they also collaborate with governmental structures in different ways. In some projects such as the ones in Santarem (Brazil) and Nairobi (Kenya), a number of NGOs and GROs are involved, working together in formal or informal networks. In the Santarem (Brazil) project, government departments such as prison services, municipal authorities, etc., are also involved. Finally, the project in La Paz (Bolivia) is managed by a disabled people's organization (DPO).

Methodology of the pilot case studies in the field projects

From the experience gained in implementing the CBR approach in urban poor communities and slums, it was decided to promote continuous exchange of experience and reflection through four main instruments — preparation of six-monthly activities reports that highlight the difficulties encountered and choices made for overcoming them; exchange of experiences through a newsletter called *Sharing*; project verification visits; and organization of exchange visits between the projects.

In October 1998, members of several projects participating in the initiative met in Bologna (Italy) to reflect on the early difficulties and methodologies of initiating the projects. During this meeting they also interacted with other project implementers who were involved in promoting community

development, health care and CBR activities in various parts of the world in differing situations such as rural communities and refugee camps, etc.

Two project exchange visits were arranged: the first one in November 1999 to Salvador (Brazil) and the second in November 2000 to Mumbai (India).

A concluding consultation of representatives of the participating projects was then organized in Bologna (Italy) from 22 to 24 October 2001 (see Annexes 1–3). It was held jointly by WHO/DAR and AIFO, with the objective of finalizing a strategic document to implement the CBR approach in urban poor communities and slums. The present document is a result of this consultation. Though it is recognized that promoting CBR in urban low-income and slum areas would include activities related to several vulnerable groups, the present document concerns itself mainly with issues related to disability.

Strategies for Implementing CBR in Urban Poor Communities and Slums

The urban poor and slum dwellers

Past decades have seen a gradual increase in disorderly and informally occupied urban areas, a result of rural–urban migration and displacement of poor population groups in search of livelihoods and survival. These urban areas are known as slums, favelas or bidonville and they are characterized by the following factors:

- High population density and lack of proper housing: Large numbers of persons are forced to live together in small spaces. For a majority of poor persons living there, the living spaces may be precarious structures made of mud, tin sheets or plastic, etc.
- Changing dimensions and security: Some of these areas may be relatively new and constantly threatened by bulldozers. Others may be of a much longer duration, even decades, constantly enlarging with the arrival of new persons. Occasionally the civic authorities may even legalize some areas.
- Poverty: Though the majority of the inhabitants are poor, unemployed or employed as wage earners or labourers in informal sectors, some persons may be relatively better off in certain long-standing areas.
- Services: Many of these areas do not have access to public services such as electricity, roads, hygienic services, drinking water, health care, education, etc.
- Mobility: Some inhabitants, especially in long-standing areas, may be relatively stable while others are more mobile, forced to search for alternative places or to come to the urban areas for seasonal work. Persons living in long-standing areas may have been born and raised there.
- Ethnic, religious and linguistic differences: In some of these areas, the inhabitants may belong to different ethnic, religious or linguistic groups characterized by occasional conflicts.

Persons living as squatters are often unaware of their collective numbers and identity. They may face the obstacles of the city as individuals or as family units, without any knowledge about their rights as citizens. Persons living in slums, especially those who have been there for some time, could be made more aware of their collective strength and needs.

Many need to cope with alien surroundings, different languages, cultures, ethnic origins and religions, etc. The lack of traditional support mechanisms of village communities makes them more vulnerable

to exploitation and oppression. Sometimes, it is the men who come to cities for work and leave their families behind in the villages. For survival, whole families including children may need to work or older children may need to take care of the younger siblings. Even when families realize the importance of education, their children may not have access to education because of the shortage of schools in the neighbourhood, because of teachers' attitudes or because of bureaucratic difficulties such as the lack of children's birth certificates.

Other problems resulting from this situation include violence, drug and substance abuse, prostitution, street children, etc. Lack of hygiene and basic health services may lead to higher risks of infections, ill health and disabilities with high rates of morbidity and mortality. Violence, especially towards vulnerable groups such as persons with disability, can be a serious problem.

Given all these conditions, it is difficult to visualize a "community" among the urban poor and slum dwellers. However, family members, friends, neighbours and concerned persons in the low-income and slum areas can constitute a first level of "community". In addition, in long-standing slum areas there may be persons who are recognized as leaders because of their political, civic or religious role. There may be organizations or informal groups of women and/or youths in the slums and urban poor areas. Although slum dwellers are usually seen as "receivers" of aid, they may still have their own resources and a willingness to help others who are even more vulnerable.

Initiating CBR

Concerned parents or local grass-roots groups can initiate a CBR programme in an urban poor area or slum. Sometimes it may require the intervention of external facilitating agencies, which could be governmental authorities or local nongovernmental organizations.

Before any such programme starts, the communities need to have some familiarity with and confidence in the persons belonging to the initiating agencies. At the same time it is essential for the initiating agencies to have a good knowledge about the people and their main problems. Thus, a CBR programme should be seen as a slow and gradual process.

In addition, before any CBR activity starts, it is necessary to define the target area and to identify key persons and local institutions and organizations already present in the area. It is important to discuss and define the activities needed with community members and community leaders.

It may not be very easy to organize a meeting with community members, especially the family members of disabled persons and other vulnerable groups, to explain the ideas and to set in motion the first discussions, especially if the persons promoting the CBR programme are perceived as outsiders.

One possible initial step is to introduce a basic service, such as a nursery school or basic health care, or to strengthen an existing service, which would give the community a chance to interact with the initiating agency and to build familiarity and confidence. It would also allow the agency staff to learn about and discuss community needs, priorities and problems. Existing local initiatives started by concerned parents and groups can be very important and all those concerned can be involved in discussions and planning from the outset.

The identification and involvement of community leaders including influential persons, political and/or religious leaders become critical in this initial phase. For example, it is helpful to involve and inform local authorities such as civic authorities or police, etc. Both these activities may be difficult and require persistent and repeated efforts.

Identification and recruitment of key personnel belonging to the target communities and representing the religious or ethnic composition of the area are effective in building relationships of trust and confidence with the outside agency. More time and meetings may be needed to involve the communities in urban slum and poor areas as compared to communities in rural areas.

Understanding the needs

Carrying out a survey to identify disabled persons and other vulnerable population groups is helpful in defining the magnitude of the problems and for promoting discussions with local communities about priority activities and their implementation methodologies. However, such surveys may build up unrealistic expectations and lead to disillusionment even before the start of activities. Poor and slum communities may have past experience of surveys, making them suspicious and uncooperative.

Some project implementers prefer to proceed through gradual diligence and awareness building by promotion of dialogue and discussion with interested families and community members, rather than by promotion of any specific interventions. In this way, through a consultative process the communities themselves develop a plan of activities and the method of implementation. In such an approach, identifying the disabled persons and target groups in the community may be a slow and gradual process.

Other project implementers prefer to start with a gradual survey and, as the survey proceeds, promote certain activities, especially those that facilitate access to existing urban services such as hospitals, schools, vocational training, governmental assistance, etc. This may help in “spreading the word” among the target communities, thus improving collaboration for subsequent surveys.

The planning process should involve people in defining their needs and priorities, which may change with time. Thus, understanding the needs and planning of activities should be seen as an ongoing process.

Empowerment and community participation

Empowerment means that disabled persons and other target groups along with their family members and concerned persons in the community are aware of their rights and their collective strengths, have the necessary skills and resources to ensure access to existing services and facilities, and can take advocacy action to demand equal opportunities. Enabling empowerment is closely linked to community participation and ownership of the different aspects of the CBR programme. Promoting and/or strengthening DPOs and self-help groups (SHGs) is an important part of this process.

For example, countries have laws concerning access to transport and allowances for disabled persons about which persons living in urban low-income and slum areas may not be aware. A CBR programme in such a situation can provide information about these laws. Persons having this information may not know exactly how to benefit from such laws and how to fill in the forms to obtain the required certificates, identity cards and other documents; CBR programmes can provide practical skills and help in this respect. Persons having both the information and the skills may still be unable to obtain the required documents because of a lack of financial resources necessary for the request, and the CBR programme can help by promoting savings and credit funds to provide loans in these situations. Initially such information and skills may depend entirely on the staff of the initiating agencies, but persons from local communities can eventually be trained to take on this role.

Promoting DPOs

CBR programmes can help in creating links between the communities and existing DPOs in the cities. They can also help in bringing together persons with disabilities, family members and other concerned persons in the formation of such local organizations. Through support for management and leadership training such organizations play a vital role in the CBR programme, for example, in awareness and information activities, as well as in running cooperatives and savings and credit funds.

CBR and community committees

Community committees may already exist in the urban low-income and slum areas, some of which may be involved with specific issues such as land rights and may not understand or regard disability as a priority issue. However, it is always important to try to inform and involve such committees in the CBR programme so that a CBR committee comprises disabled persons, their organizations, family members, concerned citizens, community leaders, etc. Persons representing specialized institutions that provide services to these areas may also be represented on such committees. To have a CBR committee that plays a role in management is the ideal goal for the CBR programme.

Role of public authorities

Persons living in the slums and the urban poor are citizens with rights equal to those of other citizens in the country. Involving local authorities to ensure public services and collaborating with existing governmental institutions are thus very important for CBR projects.

Role of CBR personnel

Initially the promotion of CBR activities in low-income and slum areas may require paid staff to work with the community. Such staff could ideally be from the target communities themselves; however, it may not be possible to find persons with the required training. The selection and training of paid staff to work in low-income and slum areas require special attention. The training must emphasize their role as facilitators and the overall goal of community takeover and ownership of the activities.

Role of community volunteers

Difficulties in finding community volunteers and their quick turnover are problems faced by CBR programmes and these difficulties may be accentuated in urban low-income and slum areas. However, there are examples of successful involvement of community volunteers in various projects, especially from among the disabled persons and their family members.

Activities

Health and rehabilitation

Disabilities are sometimes equated with sickness, and persons with disabilities may be erroneously seen as sick persons. This may not be true for many persons with disabilities who are healthy. The CBR programme is able to play a key role in increasing the accessibility of existing institutional rehabilitation services in the cities for persons living in urban low-income and slum areas. The disabled persons or other target groups and family members can be accompanied to the rehabilitation services, and the bureaucratic formalities and procedures, etc., explained. Eventually, such roles can be taken over by local skilled persons in the communities.

However, such accessibility may be limited because of lack of time, and financial resources and community support may be required. Personnel, especially specialists from the existing institutional services, may be invited to visit the low-income and slum areas and become better acquainted with the needs and constraints of such communities.

The use of manuals such as the *WHO Manual on CBR* is important in providing knowledge about the causes and mechanisms of the various disabilities, as well as the range and limitations of rehabilitation activities offered to the disabled persons and their family members.

Education

CBR programmes can play a key role in creating awareness about the importance of education and in facilitating access to local schools. These programmes can also find solutions to obstacles such as the lack of a birth certificate.

CBR programmes can participate in creating awareness about the needs of disabled children among local schoolteachers and their training needs. It is important to promote the concepts of inclusive education.

In the community itself, the CBR programmes can help in promoting local nursery schools and ensuring that young children with impairments have access to these schools.

CBR programmes can also promote formal and informal education activities for adults at several levels.

Work and income generation

CBR programmes can play a key role in increasing accessibility of disabled persons and other target groups in existing services of vocational and skills training in the cities. This would provide a wider range of income generation activities.

CBR programmes can promote awareness about existing laws related to the employment of persons with disabilities. Those who are already employed may also appreciate support, and employers should also be made aware of disability issues.

CBR programmes can also promote training to create cooperatives and savings and credit funds. This would encourage self-employment. Information about obtaining loans, managing funds, bookkeeping, etc., could be included. Promoting self-employment is very important and persons arriving in the cities from rural areas may need support to integrate in the city and find their livelihood.

CBR resource centres

Lack of living space and overcrowding are key issues in urban low-income and slum areas. Identifying an actual physical space where disabled persons, other target groups and family members can meet together and organize some of their activities is very useful in such a situation. Suitable spaces in existing infrastructures are often identified by the communities themselves — these spaces may be used only on specific occasions or during certain periods of the day or week for CBR-related activities. For example, in the slum CBR project in Mumbai (India) such activities take place in a building provided by different religious organizations; in the urban low-income area CBR project in Alexandria (Egypt) such activities take place in a school building; while in a slum CBR project in Korogocho (Nairobi, Kenya) a small hut was built specifically for this purpose. Such spaces are considered as “CBR resource centres”.

Resource centres are also useful for organizing technical support, training activities, etc., and they help community members to access learning resources such as books and toys. It is important to promote networking with other existing resource centres in the cities. A resource centre effectively provides an “address” for the community to receive communications and identity for the activities.

Creating links with other existing programmes

Several organizations and development programmes may be active in the same area, for example, organizations involved in vaccination programmes, women groups or education. Such organizations may be linked directly or indirectly to governments or they may be NGOs. The CBR programme should try to create links with these other programmes in order to promote an increased awareness about the situation and needs of disabled persons and other vulnerable target groups. In this way the other organizations can include them in their planned activities. Such links assist in organizing joint activities to reinforce messages and skills, and to economize resources. Finally, such links may help to understand the community’s involvement in different activities and to promote more realistic expectations from the CBR programmes.

The other organizations operating in these communities may be using charitable or intervention approaches, which make it very difficult for the CBR programme to promote community involvement and ownership. In such situations, it may be constructive to open a dialogue with the organizations to discuss the difficulties and strategies. CBR is a part of community development and it can act as a catalyst in bringing together community members and in engaging the more vulnerable among them in development activities.

Monitoring and evaluation

Apart from data on the number of disabled persons and other target groups benefiting from the different components of the CBR programme, key information about access to the existing city services and community participation and ownership needs to be identified and monitored. These aspects also need to be considered for evaluation and impact assessment, with a view to the sustainability of the CBR programme activities. Ideally, target groups and communities should be involved in the analysis and understanding of such monitoring and evaluation exercises, and their input used to plan new strategies and the future course of action. Information about the community and its needs is a resource for the community.

Conclusions

Promoting CBR activities to empower disabled persons and other target groups in urban low-income and slum areas, and to increase their access to the available city services is a slow and gradual process. This process is based on recognition and reinforcement of existing resources in the communities and in the neighbouring cities, in collaboration with other organizations and programmes active in these areas. The projects that initiate such a process must be of a limited duration and with a gradual phasing out of the external agencies, so that the process may continue in the communities. Local institutions and grass-roots organizations are very important for the involvement of persons with disabilities and their families.

The Process

The present document on strategies for implementing the CBR approach in urban slums and low-income areas is a result of an ongoing and intensive process of networking between the different pilot projects participating in this initiative. As more than one participant at the Bologna meeting in October 2001 observed, visiting different projects, sharing experiences and learning from each other's ideas, difficulties and successes has been a very enriching and empowering process. The exchange visits which involved representatives of other countries coming to learn about their work, created pride and motivation in the slum communities. The following is an attempt to provide a glimpse of this process of networking among urban slum communities from different countries.

The consultation in Manila (Philippines) in 1995

The workshop was organized in Manila from 25 to 29 September 1995 with the *aim of exploring the relevance of CBR philosophy to those impoverished in the slum communities*. Participants in the consultation came from nine slum communities located in Brazil, India, Kenya, Philippines, South Africa and United States of America.

At the time of the meeting the DAR Team was still called the Rehabilitation Unit, and represented by Dr Enrico Pupulin, who continued to follow this initiative until its conclusion in October 2001 in Bologna (Italy). Two other units of WHO in Geneva were also participating in the initiative: Treatment and Care Programme on Substance Abuse, and Mental Disorders Control Programme on Mental Health.

The background paper prepared for the consultation considered the challenges of implementing CBR among urban slum communities:

The philosophy of CBR is immediately persuasive, but the challenge now is to translate philosophy into action. The immediate task is to examine how principles of CBR can be enacted within the ethos of slum communities. Is community involvement in the area of rehabilitation realistic within impoverished urban communities? Is it possible to develop rehabilitation as a "process" in which a number of persons are involved, rather than as a "product" which is dispensed to others? Indeed can CBR prove to be a catalyst in the promotion of an integrated approach to development within slum communities?

The following issues were discussed during the Manila meeting:

- Is disability a perceived priority within the slum community?
- Is community involvement realistic when people are engulfed in poverty?
- Do the settlements of the urban poor have the traditional community organizations and social support networks seen in rural communities?
- Can community resources be mobilized to meet some of the needs of persons with disabilities? What are these resources in slums and how could such potential be mobilized?
- Is the empowerment of persons with disabilities a realistic goal amidst the squalor of big city slums?
- Is the concept of working with volunteers any more than a romantic notion within slum communities?
- How can the cooperation among public services in health, education and labour be reinforced?
- Who are the leaders in these communities and are they likely to be altruistic enough to collaborate with a CBR initiative?

- How pervasive is the criminal ethos within the slum? Is the CBR intervention likely to be met with support or suspicion?
- Is there a danger that the CBR programme will be dismissed as an irrelevance by a people who are more consumed by issues of survival?

The idea during the Manila discussions was to propose CBR activities for disadvantaged groups, including persons with physical or mental disabilities, persons with harmful or dependent substance abuse, unsupported mothers and the elderly, because of the following observation:

From the early consultation with slum dwellers and those working in this area it became clear that a narrow definition of disability would be irrelevant to such a population. To be meaningful a wider concept of disability needs to be formulated. A wider definition will attempt to respond to broader challenges of Mental Health and Substance Use in addition to the more traditional conception of domains of a “disability programme”.

After in-depth discussions, the participants of the Manila consultation agreed that there was a need for a new approach based on multisectoral cooperation, equity and solidarity, in the context of increasing urbanization and poverty, which would reach disabled persons and socially disadvantaged groups. They agreed that the CBR approach could be applied in urban slum communities.

After the Manila meeting

The centres participating in the Manila meeting were invited to present pilot proposals to WHO/DAR in order to test the strategies recommended in the Manila report for the implementation of the CBR approach. During 1996, proposals for pilot projects were presented by five of the nine slum communities represented in the Manila meeting:

Mumbai, Maharashtra, India	Dr Usha S. Nayar
Nairobi, Kenya	Fr Alex Zanotelli
Quezon City, Philippines	Fr Norberto L. Carcellar
Salvador, Bahia, Brazil	Ms Cristina Firmo Foglia
Santarem, Para, Brazil	Dr Eugenio Scannavino

Funds were approved by WHO/DAR during 1996 and these five projects started in early 1997.

Agreement between WHO/DAR and AIFO

In early 1997, AIFO signed an agreement with WHO/DAR to follow up the pilot projects participating in this initiative. Under the agreement, Dr Sunil Deepak was nominated as project manager for the initiative and AIFO consented to provide part of the resources to some of the pilot projects.

Additional pilot projects

Three more projects working in urban slum and low-income areas joined the initiative during 1998 and 1999:

Alexandria, Egypt	Mr Emad Abdel Messih
La Paz, Bolivia	Ms Elisabeth del Carmen Osorio
Makassar (Ujung Pandang), South Sulawesi, Indonesia	Dr Nurshanty S. Andi Sapada

Sharing of experiences and learning from each other

Overall, there were five meetings when representatives from the pilot projects participating in this initiative assembled to visit each other's projects, to share experiences and to reflect together. These five meetings were organized as follows:

In 1995, first meeting and exchange visit in Manila, Philippines

In 1998, second meeting in Bologna, Italy

In 1999, third meeting and exchange visit in Salvador, Brazil

In 2000, fourth meeting and exchange visit in Mumbai, India

In 2001, final meeting in Bologna, Italy

Apart from the meetings and exchange visits, an information newsletter entitled *Sharing* was produced for internal circulation among the pilot project participants. Annex 4 presents some significant examples from *Sharing* in order to illustrate the process of learning from each other's experiences.

Annex 1. Participants at the Final Meeting

Bologna, Italy — 22 to 24 October 2001

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Annex 2. Agenda of the Final Meeting
Equal Opportunities for All: A Community Rehabilitation Project for Slums
Bologna, Italy — 22 to 24 October 2001

22 October	09:30	Inauguration	
	09:45	Background information and goals of the consultation	
	10:15	Coffee break	
	10:45	Experience of CBR in Quezon City, Philippines	
	11:30	Experience of CBR in Mumbai, India	
	12:15	Experience of CBR in Ujung Pandang, Indonesia	
	13:00	Lunch break	
	14:30	Experience of CBR in Alexandria, Egypt	
	15:15	Coffee break	
	15:45	Experience of CBR in Salvador, Brazil	
	16:30	Experience of CBR in Santarem, Brazil	
	17:15	Experience of CBR in La Paz, Bolivia	
	18:00	Conclusions for the day	
	23 October	09:00	Summary from Day 1 Lessons from Salvador meeting Lessons from Mumbai meeting
10:00		Coffee break	
10:30		Looking at the revised strategic document: Prerequisites Target groups Multisectoral approach	
13:00		Lunch break	
14:30		Looking at the revised strategic document: Community volunteers Community involvement Referral support Monitoring and evaluation (Coffee break at 15:30)	
18:00		Conclusions for the day: How to promote the new strategic document Drawing the final conclusions	
24 October		10:00	Distribution of Final Document Visit to Disability Documentation Centre in Bologna Meeting a group of disabled activists Conclusions

Annex 3. The Final Meeting in Pictures
Bologna, Italy — 22 to 24 October 2001



Dr Usha S. Nayar (left) presents a report about activities of the TASH foundation in Mumbai (India), while Dr Enrico Pupulin (WHO/DAR, Geneva) and Dr Nurshanty S. Andi Sapada (South Sulawesi, Indonesia) listen



Anne Finkelstein (accompanying Vic), Vic Finkelstein (a disabled activist from UK) and Prof. Urbano Stenta (representative of the Ministry of Foreign Affairs, Italy) during the meeting



From left: Fr Norberto L. Carcellar (Quezon City, Philippines), Dr Eugenio Scannavino (Santarem, Brazil), Dr Giovanni Gazzoli (Observer, AIFO), Ms Cristina Firmo Foglia (Salvador, Brazil) and Dr Nurshanty S. Andi Sapada (South Sulawesi, Indonesia) during the meeting



From left: Ms Alicia Limachi (accompanying Elisabeth), Dr Sunil Deepak (Project Manager for initiative, AIFO), Dr Enrico Pupulin (WHO/DAR, Geneva) and Ms Elisabeth del Carmen Osorio (La Paz, Bolivia)

Annex 4. Extracts from the *Sharing* Newsletter

SHARING

(Extracts from January 1999 Issue)

About SHARING

This Newsletter is a forum for promoting discussions among the persons involved in pilot projects under the initiative “Promoting Community-based Rehabilitation (CBR) in Vulnerable Groups” of the Disability & Rehabilitation team of the World Health Organization (WHO/DAR) in different countries and to share these discussions with other persons and Organizations interested in disability and rehabilitation issues. This initiative focuses on two main areas – urban slum and poor communities; and persons living in the refugee camps.

At present we are planning to bring out four issues of the Newsletter every year. The Newsletter will also be available in printed form for those who do not have access to Email. If you would like to receive this Newsletter regularly or you want us to send it to some one, please do write to us. We look forward to your comments and suggestions as well.

Pilot projects involved in “CBR in Urban Slum Communities”

- A. CBR Santarem Project in Brazil: This project is being managed by Dr. Eugenio Scannavino Netto and involves a number of non-governmental Organizations (NGOs) and municipal authorities in Santarem city of Brazil. The NGOs involved include different Organizations of disabled persons as well. Thus the project is trying to promote awareness about disability issues and CBR activities through Organizations which were already active in the sub-urban slum areas in Santarem. The representatives of Organizations involved in the project have together constituted another Organization called “CBR – Santarem” that manages the funds provided by WHO/DAR.
- B. Building up the Future - community action towards disability in Salvador de Bahia in Brazil: This project is managed by Ms. Cristina Firmo Foglia of Talita Training Centre of Salvador. The project based in Fazenda Coutos III slum of the city was planned in three phases. Up till now the first two phases (Creating Awareness and Understanding the Needs) have been carried out and the third phase (Defining strategies and Implementation) is being planned. At present the project has decided to limit its activities to children and young adults. Apart from disabled persons, the project is also working for persons with problems of drugs and alcohol addiction.
- C. CBR Project - Korogocho in Kenya: This project is managed by a community committee, presently chaired by Ms. Jemimah Nyakio. Apart from the members of the committee two other persons play an important role in the project - Fr. Alex Zanotelli and Mr. Gino Filippi. The project is based in the Korogocho slum area in the periphery of Nairobi. The most important problem faced by the inhabitants of Korogocho is the fear of bulldozers, periodically razing down their houses to the ground. Starting with this common fear, the community committee has taken up initiatives related to disability and CBR, the problem of street children and their addiction to glue sniffing, alcohol and drugs, etc.
- D. Community-based rehabilitation in Alto Lima area of La Paz in Bolivia: This project is managed by Ms. Elisabeth Osorio who represents an Organization of disabled persons (DPOs). Among other activities, the project has decided to strengthen capacity building activities and promote awareness about disability issues among the grass-roots organizations existing in Alto Lima area of La Paz like vaccination committee, Mother’s clubs, Youth groups, etc.
- E. Samarth – A CBR project on disability in the slums of Mumbai, India: This project is managed by Dr. Usha S. Nayar of the TASH Foundation, an NGO. TASH sees its role as a catalyst or

mediating agency in mobilising community resources and networking within and between the institutions/systems/individuals/specialists. In her report Dr. Nayar writes, “*People living in the slum community do not belong to the same caste, have different origins (geographic and ethnic), and also belong to different religions - which in the present political context is another potential conflict point. What binds them all, is that bleak and indifferent surroundings are the same disadvantages, be they social, economic, emotional or physical*”.

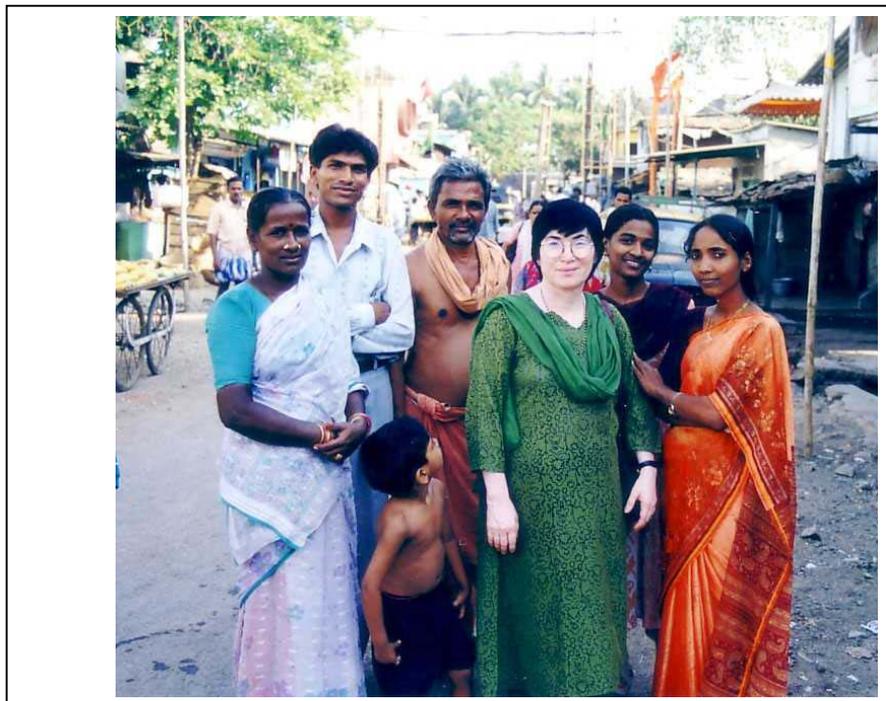
- F. Payatas CBR programme in Quezon City, Philippines: This project is managed by Fr. Norberto Carcellar of the Vincentian Missionaries Social Development Foundation. The project works mainly through the involvement of community volunteers. Barbara Panther, the trainer and co-ordinator for the CBR programme forms part of a team, which also has mothers, youth, disabled persons, volunteers, etc., representing the community. Apart from training on causes and management of disabilities, the project also carried out a theatre workshop in 1998. At present the project is planning expansion to two other areas (Barangays).

SHARING

(Extracts from June 1999 Issue)

SAMARTH Pilot Project, Mumbai, India (From a report by Dr Usha Nayar)

TASH (Technology and Social Health) Foundation is a registered NGO based in Mumbai, India. The Foundation facilitates Research cum Action Studies. In the last seven years, many studies and field projects related to the deprived and the vulnerable groups, be they street or slum children, or the disabled persons in the slums have been initiated.



Dr. Usha Nayar with some volunteers of TASH team in Cheeta Camp

Mumbai (erstwhile Bombay) is home to approximately 12 million people, apart from the several thousand migrants and visitors from all over India. The growth in infrastructure has not kept pace with the rapid growth of the city. The most visible illustration of this lopsided development is the presence and proliferation of slums all over Mumbai.

CBR project in Bhimwadi and Cheeta Camp Slums: The residents of these slums largely provide the informal business sector with muscle and a pliant labour force, without the benefits of labour laws and legislation. Further, illiteracy and the poor living conditions make the slum dwellers susceptible to several health and related problems. The plight of the disabled persons in such a situation is very difficult.

Thus, for any project to be sustainable there has to be an Organization with grass roots presence in the slums. It also needs the support and co-operation of the community. TASH fulfils all these requirements.

Project SAMARTH has been initiated in this context. The three core components viz. the slums, the disabled persons, and their rehabilitation, through and by the community, form the basis of this project initiative.

The Plan of Action: in operational terms the project aims to identify the disabled persons in the slums, assess their needs, understand the views of their support systems, and involve the community to initiate the rehabilitation process.

The rehab process would necessarily involve co-ordination between specialised experts/institutions, the Foundation and the Community.

A target group of about 5000 slum households situated in the slum settlements of Govandi and Mankhurd were selected to be the project site. In the process a pilot study to establish and sustain a Community Based Rehabilitation process has been initiated with a small support from WHO/DAR. In this process, the Foundation's essential role is:

- ❑ To identify and support community resources (human, structural and others)
- ❑ Facilitate access to rehabilitation services
- ❑ Sustain community involvement through training, advocacy and hands-on involvement.

The entire Project processes, the stages of implementation, the insights drawn from its evolution, and related observations would be documented. This is necessary as the residents in the slum settlements might (and do) have different ethnic, social and religious traditions. What holds them together are the shared poverty, deprivation and its typically difficult living situations. The paradox here, for people in the slums and the urban poor among them, is the gap that exists between the presence of specialised world-class institutions in the city and the difficulties slum dwellers have in gaining access to these.

The objectives of the project include setting up a network of volunteers, community members, elders, local agencies, media professionals and other NGOs to support advocacy and issues related to accessing existing institutions and statutory resources.

A project of this kind (whether Pilot or otherwise) does trigger some expectations from the respondents and the Community. The Foundation feels a moral responsibility towards these identified disabled persons and their families, and we have committed ourselves to the development of a mechanism that is all inclusive and would have a strong slum based volunteer work force.

Some of the important activities carried out by the Project: include disability awareness campaigns, creation of self-help groups, identification and training of community volunteers, referral support for medical rehabilitation, counselling for vocational training, Organization of camps, Organization of cultural and social events like music, theatre and dance programs.

Results of these activities have been enthusiastic. For instance Nisha, Sanjay and Laxman underwent training in sewing, gardening and screen-printing in spite of huge difficulties. The sense of achievement and a feeling of being involved in useful activities have transformed their daily lives and along with that of their families and the neighbourhoods.

Counselling takes on a new and important dimension in the context of rehabilitation. Indians not only have strong traditional beliefs, but also observe most customs and rituals associated with the ancient traditions. For instance Aparna, a young girl with disability, believes “it is my own Karma, which is responsible for my situation”. Such strong beliefs associated with disability make it very necessary to counsel the disabled persons, their families and relatives. Counselling and awareness activities go in tandem here, and the idea is to build an attitude that includes self esteem and the ability to cope and resolve the stress, in disabled persons as well as within the family.

We realise that Rehabilitation is an ongoing and long drawn out process, which does not end with the provision of callipers, hearing aids, or eyeglasses. While physical and vocational rehabilitation does promote a feeling of selfworth, it is finally the emotional and psychological rehabilitation that integrates and provides a feeling of completeness.

The concept of self-help group emerged with this idea, that all of us need to share our feelings and emotions, and also to express our feelings of rejection and frustration. The disabled persons in the slums have very little interaction with their parents and peers. These also provide a forum for discussing social, psychological, sexual, educational, and emotional needs of the disabled persons.

New projects participating in the CBR in Slums initiative

There are two new projects which have accepted to be the part of this group and to share information and experiences with the other participating projects. These are:

- *Ujung Pandang CBR Project in Indonesia:* This project is part of a provincial CBR programme in South Sulawesi province of Indonesia, which started in 1996. Dr. S. Nurshanty, the provincial CBR co-ordinator is the project manager. It was decided to start a CBR project in Ujung Tanah suburb of the provincial capital, Ujung Pandang, to study the strategies of CBR implementation in poor slum areas. The project works through the governmental health structures involving different governmental departments (health, education and social welfare) and through an Indonesian NGO of women called PKK. The project has identified community volunteers who have been trained in CBR and are being followed by a team of local supervisors composed of a nurse, a schoolteacher and a social worker. A survey has been carried out in the community to identify the existing persons with disabilities and their rehabilitation needs. In collaboration with the provincial Psychiatric hospital, the project has started a home-care program for persons with mental illness. In collaboration with the regional leprosy institute, the project has promoted specific activities for rehabilitation of leprosy affected persons. Among the different activities carried out by the project are community awareness campaigns, savings and credit funds, self-help groups, vocational training courses, inclusive education, etc. This project receives support from AIFO.
- *Alexandria CBR program by SETI in Egypt:* This project started in 1995 by an Egyptian NGO called SETI and Dr. Alaa Sebeh is the project manager. The project covers five poor suburban areas in the city of Alexandria (Karmouz, Hadara, Smouha, Mountaza and Bacchos). The project works in collaboration with Governmental Mother and Child clinics along with community volunteers, parents of disabled children and community CBR committees. Till now the activities of this project had been restricted mainly to children with mental disabilities. In future the project plans to enlarge its activities to include all persons with disabilities and to expand the activities to three new areas in Alexandria. The project is funded by AIFO.

SHARING

(Extracts from October 1999 Issue)

Letter from Payatas Quezon City - Philippines

Dearest Sharing,

I am Arlene, I have polio in both of my legs and I work as a staff for the CBR program. I have been involved with the program since 1997. But before becoming a staff I was just a client, later I became a volunteer staff helping in preparing for the learning materials. My work from being a volunteer changed also as I embraced a bigger responsibility, I do now area visits, facilitate and lead the newly organized Disabled Person Organization to which we have given the acronym SAMAKAPA that in English means "Join Us".



Arlene (in the wheelchair) with friends and volunteers

Working for the program has taught me so many things, I have learned new skills, I was able to see so many things that I might not have seen because I was not able to finish school.

Before, my self-esteem was very low. I found it very difficult to relate with people because I always feared that they might not like me, or they might tease and make fun of my condition. For seven years I kept myself isolated from people. Now with the program, I have discovered a different person in me. I have found my strength and my capabilities, now I am using it to help others that might be in my exact condition before CBR came into my life. It is so wonderful; it fulfilled my dreams of learning, I might have stopped school years ago, but now, I am learning lessons greater than whatever school might give to any of its students and that is to serve and to love others.

CBR brought me a new world, I never thought that I could travel to other places because of my condition, but I am able to do it now. There is no greater desire in me but to be able to serve, help more the disabled youth to realize that they have rights, that we have equal chances with the able people and that there is so much in life that we have to see.

Sincerely yours,

Arlene

SHARING

(Extracts from March 2000 Issue)

Santarem CBR Project (Brazil) – (from a report by Dr Sunil Deepak)

In 1995, Dr. Eugenio Scannavino Netto, Co-ordinator of a community health care project, covering rural communities in Santarem municipality (Para State in north-east Brazil), participated in the Manila Conference on Implementation of CBR in Slum Areas. Following this, Dr. Scannavino organised a meeting of different governmental and non-governmental Organizations active in Santarem municipality for issues dealing with vulnerable groups (disabled persons, drug and alcohol dependent persons, street children, prisoners, HIV-positive persons, etc.) to discuss with them about the CBR approach. As a result of this meeting, different organizations, both governmental and non-governmental, decided to create the Santarem CBR committee. This was a new way of looking at CBR by working together with different Governmental and NGO partners. However, after an initial phase of enthusiasm, some difficulties arose. Two main reasons were proposed for these difficulties: confusion in the project identity and leadership; lack of motivation in some of the CBR Committee members.



The logo of Projecto Saude e Alegria, one of the partners of Santarem CBR project

Finally, at the end of September 1999, a two day workshop of the Santarem CBR Committee was held. At this occasion, most of the representatives of different member Organizations were changed and elections were held for all the Organizational posts. The new Santarem CBR Committee, headed by Mr. Telmo Limo (President of DPO ADEFIS), discussed the problems faced by the last committee and proposed some changes, in the way of working of the Committee for the future.

The Committee realises that it is unrealistic to plan activities jointly for the CBR project, which need to be carried out by the Committee members. This is because all the Committee members have responsibilities in their own Organizations and it is difficult for all of them to come together at the same time for long periods. Thus the Committee has decided that each member Organization can plan its own activities related to CBR and present the proposal to the CBR Committee for funding from the WHO/DAR funds. The Committee will try to promote collaboration and joint actions by different partners, wherever possible. At present the Committee is trying to define the criteria for the activities

which can be supported as part of the CBR project, though they feel that one of the most important criteria will be to ensure that the Organization proposing an activity provides part of its own resources for it and that WHO/DAR funds can cover the remaining part. It may be possible even for other organizations, not a part of the CBR Committee, to present projects for support from these funds. Another possible criterion under discussion is to fix a limit of a maximum amount for each proposed activity. Some other considerations about the project activities include:

CBR activities: At community level, the different activities related to social services, economic rehabilitation, professional training courses, advocacy and public awareness are being developed very well and target the different vulnerable groups like disabled persons, children at-risk, drug addicts, HIV-positive persons, poor women, etc.

Strengths of Santarem CBR Committee: The composition of the present CBR Committee with the presence of different governmental (Gos) and non-governmental Organizations (NGOs) is an extremely positive aspect of this project. Such a formal mechanism of having a registered NGO, which is formed by representatives of GOs and NGOs, must be very rare, if not unique.

Weaknesses of Santarem CBR Committee: The Committee doesn't have any place or human resource person working exclusively for it. This means that the different Committee members need to find time from their own responsibilities, for the CBR Committee activities. Another problem is the differences in the roles and powers of different representatives, in their own Organizations. Thus, when the CBR Committee takes any decision, not all representatives may be able to convince and involve their own Organization, in the same way.

Opportunities for future development of CBR in Santarem: At present, Brazil is going through a process of decentralisation of health services to the municipalities. Recently, the second municipal conference on this process of decentralisation was organised. As a result of this process, municipal health councils have been created in which workers unions, citizens and NGOs are also represented. The Santarem Municipal Health Council thus has a similar composition as the Santarem CBR Committee and this development should strengthen further collaboration between governmental and NGOs in finding solutions to the health issues.

Interviewing Telmo Lima, President of Santarem CBR Committee

Telmo is 38 years old. When he was 2 years old, following an infection, he lost the use of both his legs. Moving around the city has been his greatest problem, but six months ago, he managed to get a motorised wheelchair, which has made the transportation much easier. Since last year, Telmo is the President of ADEFIS, the "Santarem Association of Persons with Physical Disabilities". In spite of its name, some persons with hearing, speech and mental disabilities are also members of ADEFIS, which counts about 830 registered members.

During the exchange visit to Salvador, Telmo was interviewed by some of the participants coming from slum CBR projects in different countries. Here are some of the questions put to Telmo and his answers:

Q. Deolinda/Brazil: Dear Telmo, is it true that you are afraid of ghosts and spirits?

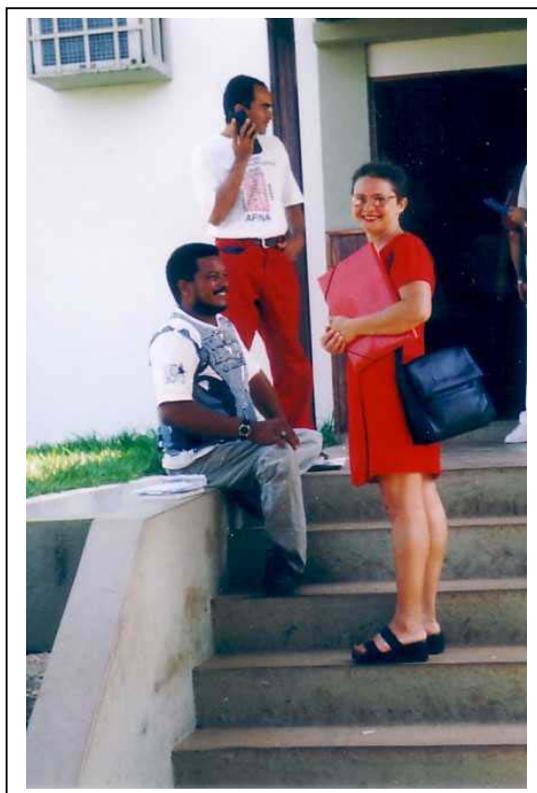
A. Telmo: I am not afraid of any spirits but I have a feeling of respect towards all beings. The only thing of which I am afraid is of being alone!

Q. Sunil/Italy: Telmo, if you could have one of the dreams be fulfilled, what would you wish for?

A. Telmo: I would like that there be peace and love in the world.

Q. Dias/Santarem-Brazil: What are the three things, which motivate you to continue your fight?

A. Telmo: I would like to change the lives of all the disabled persons. I also want to move, travel, talk with others and not remain closed and isolated at home. Finally, my motivation comes from all the persons who are members of ADEFIS and who are fighting along with me, for a better life.



Telmo (sitting) with Terezinha and Dias in Santarem

Q. Peter/Kenya: As a disabled person, how do you see the CBR concept? Do you think that it adapts to your life?

A. Telmo: I think the concept and strategy of CBR are part of a development process, so that disabled persons are not excluded and they can have access to services and make everyone understand that participation of disabled person in all activities is not a favour but a human right.

Q. Chandran/India: What do you think about the attitude of able persons towards persons with disability? Does it bother you?

A. Telmo: I think that other persons are calm, sensitive and patient towards my needs.

Q. Usha/India: How does it feel to be leader, to be in a position to motivate others and to change their lives into better?

A. Telmo: Actually I don't feel like a leader and I don't like the concept of power associated with this word. I prefer to work and discuss with others so that my "power" is shared and builds upon consensus. I prefer that we should grow up as a group.

Q. John/Kenya: What is your vision for your group in ADEFIS?

A. Telmo: I should like very much to have better rehabilitation services for disabled persons in Santarem. I hope that we, the disabled persons, will be more able and better prepared for working. I also wish for a world where everyone is more sensitive about disability issues.

Exchange visit to Salvador CBR Project (from the meeting report)

Introduction

As a part of the initiative “Promoting CBR in vulnerable groups”, a number of pilot projects were started for studying the strategies of implementing CBR in poor urban and suburban areas, following the meeting of Manila, Philippines, in 1995. The majority of these micro-projects receiving support from WHO/DAR and sometimes from AIFO-Italy, started their activities in 1997. In October 1998, some of the persons working in these pilot projects met in Bologna (Italy) during a workshop on CBR, organised jointly by AIFO and WHO/DAR. During this meeting, it was also decided to promote exchange visits between these projects for sharing of information and ideas.

The first such exchange visit was organised to the CBR pilot project in Salvador de Bahia (Brazil) from 21 to 28 November 1999. Representatives of 4 pilot CBR projects working among urban slum dwellers and participating in this initiative came to Salvador.

Participants

From India-Mumbai:	Dr. Usha Nayar and Mr. R. Chandran Nayar
From Philippines-Quezon:	Fr. Norberto Carcellar and Mrs. Minviluz Vicente
From Kenya-Korogocho:	Mr. John Kahihu and Mrs. Peter Warui
From Brazil-Santarem:	Mr. Telmo Lima and Mr. Rosival Dias

Mrs. Cristina Firmo, Mrs. Margarida Almeida De Guida and Mr. Paolo Foglia represented the hosting project in Salvador, while Dr. Sunil Deepak represented WHO/DAR & AIFO. Finally, Mrs. Deolinda Santana, head of the AIFO regional office in Brazil, participated in the meeting as an observer.

Programme of the visit

During the visit the participants divided the time between visiting the field activities of Salvador Urban slum CBR project and sharing of experiences among themselves. During the field visit to one of the communities where the Salvador CBR programme has been running, called Felicidade, some discussions were held with the community representatives. The discussions facilitated by Ms. Isable, raised a lot of significant issues, which included the following:

Activities related to disability issues: While all the projects are involved in some activities related to disabilities, none of the projects, except for Quezon-Philippines, have carried out any training of parents and/or disabled persons or used the WHO manual. All the projects have instead worked on increasing the access of existing medical services to the target population in the slums.

Other socially disadvantaged groups: Persons affected with alcohol and substance abuse are another common area in which all the projects have been active. Activities related to children at risk were also a priority for many of the participating projects.

The role of other important issues like land-tenure: The group agreed that the question of land-rights was the one perceived as the most important issue facing slum dwellers. However it was felt that the land-issue related to all the population of the slums and not only to the disabled persons.

Vocational and skills training: Almost all the projects felt that the livelihood issues were fundamental in the priority needs of disabled persons. For this, most of projects were involved in the Organization of specific training courses or in making links with vocational rehabilitation institutions existing in the cities. However surprisingly, except for the CBR project in Quezon (Philippines), the other projects have not been involved in any saving and credit scheme experiences.



Cristina Firmo (right) presenting the volunteers of Salvador project during exchange visit

The team members from Salvador raised another aspect of this issue: “*CBR is part of a process of community empowerment and development. In such a process, which should be managed and decided completely by involved communities, how correct it would be to introduce concepts like Savings and Credits, if these are not perceived by the communities as a relevant issue?*” Other participants felt that the communities need to learn about the different possibilities and then can be asked to take their own decisions.

Advocacy activities: Most of the projects had been involved in public awareness and advocacy for human rights issues of disabled persons. Getting “disability certificates” from the governmental services, which can allow certain concessions regarding transport costs, pension benefits, etc., is another area which challenged the projects with various degree of success.

Education: Though formal and informal education of disabled children was mentioned as a concern by different projects, not many specific activities were mentioned during the presentations about these aspects.

Data collection about disabled persons: Quezon-Philippines, Salvador-Brazil and Mumbai-India presented some information about their activities of data collection about number of disabled persons and their needs. The different approaches used by each project for this were very striking. Though this means that it may not be possible to compare the data between different projects, it does help in understanding the different ways in which communities look at disability needs. Korogocho-Kenya and Santarem-Brazil informed the group about their plans for carrying out similar studies in their target groups. The participants also discussed the negative reactions of people in the slum areas to such surveys and studies and proposed that these should be linked to provision of services.

Strengthening of DPOs: In Santarem-Brazil, Korogocho-Kenya and Quezon-Philippines, DPOs are involved in the pilot CBR projects. It was felt that empowerment of disabled persons was the key goal of CBR projects and more efforts are needed to strengthen the roles of DPOs in CBR projects.

Recommendations of the group

The group agreed that since the first meeting in Manila in 1995, pilot CBR projects have managed to establish themselves. It was felt that the projects had reached a significant stage when a quantum jump can be made for quality of these activities. Sharing of experiences will be the key need for the future

for starting innovative activities and discussing obstacles and difficulties. Thus the group made 2 key recommendations:

- To promote discussions on key issues through E-mail among different projects.
- To organise another exchange visit to Mumbai-India in November 2000.

Salvador CBR project has taken the responsibility for preparing the full report of the exchange visits and discussions. Thank you, Cristina, Guida, Isabel and Paolo for all your hard work to make this visit a success.

SHARING

(Extracts from May 2000 Issue)

Alexandria CBR Project in Egypt

The project is working in urban and sub-urban slum and low-income areas in the city of Alexandria and is managed by Mr. Emad Abdel of SETI-Caritas Egypt. Caritas Egypt and SETI centre have been involved in promotion of CBR for children with mental disabilities for almost ten years. This has been a dynamic process accompanied with periodic participatory evaluation of the CBR approach and methodology. Thus the present project design is a result of this dynamic process in which staff of SETI and Parents Groups of disabled children have played an active and decisive role.

In each area, the CBR activities are organised in four phases. Partly these phases, especially phases 1 and 2, have already been experimented in the five areas in Alexandria where the project was started between 1992 and 1994.

The first phase includes involvement of staff working at Mother and Child Health (MCH) centres, for which an agreement exists between SETI and the Ministry of Health. SETI organises two or three introductory seminars in the selected MCH centre for awareness and for identifying the key persons to be trained. On an average 5–7 persons from each MCH are trained by practical training on “Early Intervention” for children with mental disabilities. A total of about 100 hours of training is provided, most of it at the SETI centre. As the MCH staff includes both doctors and paramedical personnel, changing of attitudes and the importance of parent and family involvement are key concepts for initial training. At the same time, community awareness and involvement activities are carried out. Thus at the end of the training of MCH staff, after 3–12 months, they can be gradually introduced to community level field activities. Small incentives are provided to the MCH staff for the field visits, along with teaching materials like the WHO manual, etc. The MCH centre participating in the project also receives some support for simple rehabilitation equipment. The involvement and capacity building of MCH personnel mean that younger children with disabilities can be diagnosed earlier, and can receive better support like early stimulation, physiotherapy, etc. At the same time, this is a key step for ensuring referral level support through existing Governmental structures.

During the second phase the emphasis of the intervention shifts to the community. CBR trainers–facilitators from the SETI centre and MCH staff make contacts with the community leaders, disabled persons and their families. MCH staff helps in identifying 4–5 suitable community health workers who are then trained by SETI staff. Community volunteers are also identified and trained. As the training starts, the community workers and volunteers start visiting the homes of disabled persons to train the families in rehabilitation techniques, and provide early intervention services, etc. At the same time, the community workers and volunteers have to attend training courses at SETI for a total of 200 hours, spread over long periods (1 year of formal training and then on the job training). All community workers and volunteers are also provided with training materials like the WHO manual, etc. During this phase, the community is asked to find a suitable space where a CBR Resource centre can be created where parents, workers and volunteers can meet regularly, organise training courses and education classes, do group activities for playing, crafts, exercises, singing, etc. Weekly meetings

at CBR Resource centres are organised, which are called “weekly clubs”. Constitution of Parents groups (Parents CBR committee) and CBR Steering Committee is promoted.

Phase three will include gradual passage of responsibility to the parents groups and CBR steering committees, which would manage the continuation of activities, with regular support from MCH staff. During this phase, the SETI staff would assume the role of providing external support and observation. This phase could be reached after 2–3 years of activities at the community level. Each CBR micro-project will be encouraged to become financially self-supporting, even though it is recognised that complete financial independence of such groups may not be easy or possible.

The last, Phase four, will be reached when the responsibility is completely passed to the CBR committee and the MCH team and the CBR program belongs to them. Reaching this phase will be the final goal of the project and it remains to be seen if it will be feasible.



Volunteers, parents and children in a community resource centre in Alexandria

Each area has a community resource centre where parents, disabled children, volunteers, MCH workers, etc. meet weekly. The community resource centres receive some simple equipment like black-boards, stationery, colours, toys, books and some furniture like cupboards, chairs, tables, etc., to help the groups of disabled children for their weekly group meetings for playing together, having informal education, etc. Such weekly meetings called “clubs” are moments of joy, play and fun for all concerned. Thus while the mothers can sit together and with the help of a community facilitator, discuss their problems and ideas, other community volunteers join the children for singing songs, playing, etc. Community centres can be in school buildings or mosques or other suitable buildings, provided to the project by the community. Such centres are the focal points for developing all the project activities.

The project wants to promote that all community level activities be owned and managed completely by the community CBR committees. For achieving this goal, the CBR steering committees and parents groups are supported for Organization of leadership training and building up of management capabilities for the members of CBR steering committee and parent groups in each area.

In the CBR process, linking among different children and families and their integration into social and leisure activities assumes importance for promoting community ownership of the whole process. Thus social and leisure activities include Organization of an annual summer camp for disabled children with their families, and an annual sports and cultural event which also serve for raising public awareness about the CBR program.

Meeting a volunteer from Alexandria CBR Project

Ms. Fawkia is one of the first volunteers of the CBR programme in the Karmouz area of Alexandria. She has been with the project for the last seven years. She was only 14 years old when she had first seen a TV programme where there was an appeal for volunteers to work with disabled children. She got married three years ago and had her first baby in January 2000. Still she continues to be an active volunteer of the CBR activities. The CBR committee in Karmouz collects funds from the general public and this allows them to pay a small amount of 30 Egyptian Pounds per month (about 8 USD) to experienced volunteers like Fawkia. She is really happy with her role and feels that this work has brought her recognition and respect from the community and from her husband's family. She works every day for about 6 hours for the project.

SHARING

(Extracts from October 2000 Issue)

Community based Rehabilitation in Ujung Tanah - Indonesia **A study about the situation in the slum area**

Ujung Tanah is a slum area in Ujung Pandang, the capital of South Sulawesi province in Indonesia. The CBR programme in Ujung Tanah started only in 1997 as a part of collaboration between the Ministry of Health of Indonesia and AIFO. Dr. Nurshanty is the co-ordinator of the provincial CBR programme, which also covers three other districts in the province.

In each area covered by the project, a multi-sectoral team of four persons have been trained. Each team is formed by a health worker, a schoolteacher, a social worker and a volunteer from a women's Organization called PKK. These four persons are the local supervisors for the CBR programme and they train community volunteers and supervise their work.

Apart from home visits for transfer of knowledge and skills to the disabled persons and their family members, the community volunteers also promote inclusion of children in ordinary schools, help in organising vocational training courses and promote the creation of Savings & Credit fund groups in the villages.

Immigration patterns: The majority of people living in Ujung Tanah (UT) are immigrants coming from the countryside in search of a livelihood. Most people come to UT from the surrounding Makassar and Bugis rural areas to escape from poverty in their home villages and to look for employment opportunities. Many men also come alone for short periods and the majority of them work as "tukambecak" (running tricycles for transporting people). Most families come to UT to settle permanently. They usually try to build or buy their own houses as soon as they can afford it. This entails acquiring legal rights of land use. However, the poorer sections of the population usually rent houses on short-term contracts.

Main sources of income for women: Main income generation activities for the women in UT include the following:

- Making and selling clothes; many of them make use of credit for buying the raw materials and paying them back, on selling their products.
- Petty trade (selling chocolate, vegetables, etc.).

- Working as manual labourers (sawing, carrying bags) in chocolate, pepper and rattan industries in nearby workhouses; many of them do this as second work in the evenings, for extra income.
- As domestic workers (cleaning, cooking, washing, etc.) for other families.
- Collecting and selling garbage.

Main sources of income for men: These include the following:

- Fishing and trading with fish products. Cooking and selling shark fin soup to restaurants is considered a particularly good source of income. However, fishing is not always a reliable source of income. There are times (full moon, bad weather conditions) when fishing becomes difficult.
- Working as manual labourers (carrying loads) in the harbour and in workhouses.
- Driving “tukambecak”; usually the tricycles are taken on rent and from the daily income they need to pay the rent.
- Collecting and selling garbage.

People feel that for poor families, children’s economic contribution is crucial to ensure their survival. Thus children from very poor families often drop out of school. *Girls* usually engage in domestic work for others families, *boys* generally work as labourers in the fish market or in building sites, carrying rocks.

Women have fewer opportunities to earn a living & are paid less. Children & household chores significantly limit the amount of time they can spend working outside their homes. Women in poor families are always expected to work to guarantee the family’s survival.

There seem to be significant income disparities in UT, with family income per month ranging from a maximum of about 1,500,000 Rps to a minimum of 90,000 Rps. When disabled persons find employment, they are paid less (2000 Rps per day if they work as labourers).

Housing is an important indicator of people’s socio-economic status. Apart from distinguishing between owners and renters, three kinds of houses are found UT: houses made of concrete, houses made of wood and houses made of bamboo. Most houses have corrugated iron roofs, but the poorest have roofs made of leaves.

Formal and informal social networks: When facing a problem of money, work, child minding, advice, etc., the people usually turn to their family, neighbours and friends. Traditional village & clan ties seem to be less important in the slum.

Cases of divorce or of men leaving their wives are very common. However, differently from rural areas, women who lose their husbands don’t receive any help, neither from their families nor from their ex husbands’ families. Women who have children outside marriage are usually rejected both by their families and their community.

Accessibility of rehabilitation services in UT - Health care: People usually go to the governmental health centre, & go to private practitioners mainly for emergency help. Most people feel that drugs bought from private practices are more effective. While most people regularly use the services available at the health centre, very few of them have ever been to a regional hospital or have ever consulted a specialist doctor. Most of the persons feel that specialist treatment and hospitalisation are unaffordable.

Education: Families point out two reasons for not sending disabled children to school: fear of discrimination, teasing and hassle from other children; & high costs of schooling. While the school fees are affordable, there are hidden costs of schooling (uniforms, shoes, books, etc.) which strain the already tight family budgets. For some of the persons, the choice is between feeding the family and sending their children to school. Many mothers feel that if they are forced to choose the education possibilities for their children due to lack of resources, they would prefer to educate their sons rather than daughters.

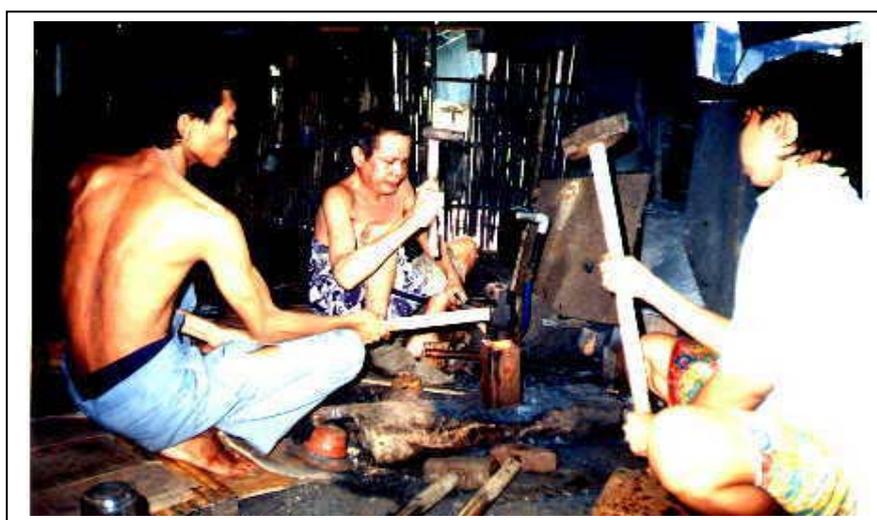
CBR local supervisors feel that most teachers and head-masters are not sensitive to the issue of educating disabled children. However, thanks to the CBR program, some teachers in UT have started being proactive in encouraging parents to send their children with disabilities to school.

Most of the persons don't have knowledge about the existence of special schools in a city while others feel that only children from wealthy backgrounds can attend them.

Vocational training: Most of the persons have no idea about the different possibilities of vocational training available in the city. CBR volunteers feel that problems of distance, costs of transport and lack of information are the main preventing factors for making better use of vocational training courses. Some disabled persons (27% according to the data available at the provincial office in the city) find some work through family and neighbours networks as labourers in the fish market, harbour and sewing.

Simple mobility aids & orthopaedic devices: Most persons know that mobility aids and orthopaedic devices are available in the city but they feel that these devices are very expensive for them. The CBR volunteers, supervisors and doctors also share this view. According to the CBR volunteers a few families have started making their own basic aids after the CBR training.

Saving and Credit Schemes: This activity has just been started by CBR. People and CBR volunteers have still little knowledge about the possibilities offered by starting savings and credit schemes. People usually borrow money from family, neighbours and money lenders.



A co-operative of disabled persons in South Sulawesi started with credit funds

Expectations from CBR programme: When asked what they expected from the program people ask for help for buying drugs and providing care to disabled persons. People already involved in the CBR programme would like to have more training from volunteers. Many persons had joined CBR programme thinking that the disabled person in their family would be cured completely. People also hope that the CBR program will help them in improving their lives by providing job training and money to start up their own businesses.

Activities of CBR programme, so far: Officially the CBR in Ujung Tanah was started in 1997 but, in reality, the activities started only in the middle of 1998. In the beginning there were training courses for local supervisor teams and community volunteers. Some of the activities carried out by the CBR programme in UT include: awareness about disability issues in the community through meetings in mosques & public places; establishment of a CBR management office in UT sub-district; house to

house survey with community mapping of disabled persons has been carried out & so far 179 persons have been identified. Upgrading training has been organised, focusing on moving disabilities, hearing and speaking disabilities and cerebral palsy. At present there are 10 supervisors & 18 community volunteers in Ujung Tanah.

Difficulties encountered by CBR teams and volunteers:

According to the volunteers, the main difficulties they face include: rejection and frustration from the families and disabled persons when they realise that the CBR programme is not distributing financial help; sometimes the improvements are very slow & difficult, so disabled persons and families get bored or frustrated; some families do not collaborate and don't want to take responsibility for doing something for their disabled family members; the programme does not provide any money to volunteers for the transport costs; there are no financial incentives in the CBR programme for volunteers.

Main difficulties faced by doctors and local supervisors in the CBR programme include: high drop out rate of volunteers; lack of co-operation with other government departments like education, labour, etc.; the district and public authorities are nominated as head of CBR committees but they show little interest in supporting the programme, apart from making public speeches.

Conclusions: The CBR programme in Ujung Tanah suburb of the provincial capital, Ujung Pandang, is still in its initial phase. The specific conditions of the slum areas pose some specific difficulties and challenges for implementing the CBR programme. It remains to be seen how the programme will overcome these difficulties and respond to the challenges.

SHARING

(Extracts from January 2001 Issue)

Promoting CBR in Urban Slums: WHO/DAR Vulnerable Groups Initiative Exchange visit to TASH Foundation, Mumbai, India, from 19 to 25 November 2000 (from the meeting report)

Introduction: In September 1995, the Disability and Rehabilitation Team of the World Health Organization (WHO/DAR) organised a meeting in Manila (Philippines) in which 9 project representatives from 6 countries were invited to discuss the feasibility of promoting the Community-based Rehabilitation (CBR) approach in urban slums. The projects, which were invited to this meeting, were already involved in development activities in a slum area.

During this meeting the participants agreed that in principle the CBR approach was feasible in the slum situations. As a result of this meeting a document was prepared, "*Equal opportunities for all: A community rehabilitation project for slums*", which provided simple guidelines for starting CBR activities in urban slum areas. Following this a number of pilot projects were identified to test the practical implementation of the guidelines.

At present this initiative is involving pilot projects in the following cities/countries: Salvador/Brazil, Santarem/Brazil, La Paz/Bolivia, Alexandria/Egypt, Nairobi/Kenya, Mumbai/India, Ujung Pandang/Indonesia & Quezon City/Philippines. This initiative will end in October 2001 when representatives from all these projects will come together in Bologna (Italy), to review the guidelines for implementation of CBR in urban slum areas. The pilot projects' main role is to test and define strategies feasible in slum situations. For promoting exchange of experiences and learning from each other, participating projects are encouraged to share information through SHARING and exchange visits. The first exchange visit was organised in November 1999 in Salvador/Brazil.



Participants of the exchange visit in Mumbai, India, November 2000

Participants of the exchange visit: This second exchange visit was hosted by the TASH Foundation, Mumbai, India, and representatives from the following countries participated in the visit: Santarem/Brazil, Salvador/Brazil, Quezon City/Philippines and Alexandria/Egypt. Observers from a slum project in Cochin/India and from the AIFO regional office in India were also present during the exchange visit.

Programme of the exchange visit: There were three main components of the exchange visit:

- A. Presentations by the representatives of each project about their activities, their constraints and difficulties, their achievements and their future plans. Some of participants had prepared charts and overheads to illustrate their activities, while others had brought video-cassettes. TASH Foundation, the hosting Organization, made a special presentation in which community workers, volunteers, professionals, disabled persons, etc., participated.
- B. Field visits to the activities of TASH Foundation and its network of partner Organizations & institutions in the city of Mumbai. The field visits provided an opportunity for interacting with slum communities involved in activities of TASH, who also organised cultural activities during the visits, which were hugely appreciated by the exchange visit participants.
- C. Discussions among the participants to analyse the different experiences and to propose future strategies. As a result of these discussions recommendations were made about the future development of this initiative.

CBR approach in urban slums: The participants took a critical look at some of the reasons for promoting a CBR approach in an urban slum situation. It was felt that the CBR approach has been promoted mainly for rural areas where there are no professionals, institutions and services for answering the needs of disabled persons. In the urban situations, usually there are professionals, institutions and services for providing rehabilitation services, so why do we need to promote the CBR approach in urban areas? The following issues emerged during discussions on this question:

- Even if rehabilitation services are available in big metropolitan cities, they are usually not accessible to the persons living in the slums. The inaccessibility may be due to economic reasons as the slum dwellers may not have resources to pay for the services or may not afford to lose their daily earnings for going to institutions. The inaccessibility can also be due to illiteracy, lack of knowledge about the services, difficulties of language (slum dwellers usually migrate from rural and sometimes, far away areas), rigid consultation timings of professionals, etc. For the same reasons, people in the slum may not know about the facilities and free services provided by Government and other Organizations.

- There is good solidarity among the persons living in slums and people are willing to help each other. On the other hand, because of cultural or social taboos, disabled children may be kept hidden. Families have a large number of children and there are other problems like alcoholism, drug-addiction, prostitution, lack of space, etc. Thus, disabled children don't receive sufficient attention. Persons with severe learning disabilities and mental illness are the most neglected.
- CBR approach can have an important role in promoting advocacy and change in public policies and social attitudes. Parents and community members, if they understand the issues related to disability and rehabilitation, they can negotiate better with the professionals for receiving rehabilitation services. CBR provides opportunities for meetings among disabled persons and their family members, for sharing of experiences, for creating a collective identity and collective action, for developing leadership skills, etc., so that disabled persons and their families are empowered.

Common areas among different pilot CBR projects operating in urban slum areas: The participants looked at the areas in which their work and experiences were common to all of them. The following issues emerged from these discussions:

- ◆ Role of the disabled persons and family members in the projects: All participants agreed that disabled persons and family members must be full partners of the projects and not seen as "beneficiaries".
- ◆ Community members in urban slums are willing to help others and projects must take care to provide such opportunities to the communities.
- ◆ The CBR project is part of community development and a tool for social transformation through promotion of activities like credits and co-operatives, fight against poverty and illiteracy, awareness about other health issues, child labour, advocacy for human rights, etc.
- ◆ Involving governmental authorities in urban slum areas may not be easy but NGOs must continue to make all the efforts to start a dialogue and to work together with existing governmental services.

Many NGOs may be present and active in urban slum areas and issues of collaboration and co-ordination may be easier to resolve at grass-roots level but dialogue must be started with NGO managers for promoting joint activities:

- ◆ Projects need simple, yet different training materials for reaching the communities, especially audio-visual materials.
- ◆ Projects need to promote inclusion of disabled children in the existing schools in the areas.
- ◆ Promote and support creation of Organizations of disabled persons and to have disabled persons in decision-making positions.
- ◆ Community volunteers are part of all these CBR projects.

Differences among the CBR projects represented in the exchange visit: The participants also looked at the ways in which their activities were different from each other and the following issues emerged from these discussions:

- Alexandria CBR project has the following distinctive features: It focuses only on a specific group of disabilities (learning disabilities) and works mainly with children even if there are some plans to gradually enlarge the activities to other groups of disabled persons; There is very close and clearly articulated collaboration between Government (Ministry of Health through Mother & Child health centres) and the NGO managing the CBR project; The project helps the communities to identify, create and run community resource centres.
- Quezon City CBR project and Alexandria CBR project both organised summer camps, where disabled persons and the family members could go out together as a group for a few days.
- Santarem CBR project makes extensive use of music, dance, creative arts and participatory methodologies in reaching the families in the communities; The CBR project is managed by a committee formed by different Government Organizations and NGOs which allows multiplication of all the project activities.

- ❑ Salvador CBR project has promoted co-operatives of mothers of disabled children as part of income generation activities; The project activities are targeted at different vulnerable groups in the communities and are not limited to disabled persons.
- ❑ Mumbai CBR project has a very strong component of research involving university professionals and yet, at the same time, disabled persons have taken an active role in assessing their own needs; The project has a big network of collaborations with institutions, professionals, Organizations in the city with important impact on improving the accessibility of existing services to disabled persons in the slums.

Future activities: SHARING would continue to be the tool for sharing experiences and ideas among the projects though they will also interact directly among themselves.

On the basis of experiences and discussions emerging from the different pilot projects, a new revised document with guidelines about implementation of CBR in urban slum areas will be prepared and distributed to all the participating centres by 31 March 2001 and they will be asked to send in their written comments and suggestions to AIFO by 31 May 2001. The corrected draft of this document will be discussed and finalised during the final meeting of participating projects, to be held in Bologna (Italy) in the third week of October 2001.

Acknowledgement: While all the participants to the exchange visit merit thanks for their active and constructive participation, special thanks are required for all the team of the TASH Foundation, the hosting Organization for their untiring efforts in making this visit a success and a hard to forget human experience, and in particular to Chitra, Ratna, Manjari, Ashok, Asha, Rekha and Bibijan.