

*International Consultation "Review of CBR", May 2003*  
**Informal Preparatory Consultation, Geneva 10 May 2001**  
**Report**

**Background:** The community-based rehabilitation (CBR) strategies were introduced almost twenty years ago. WHO/DAR is planning an international consultation in October 2001 to review the present strategies of CBR, its impact on the lives of disabled persons and communities, its strengths and constraints.

*Government of Finland* has agreed to host this international consultation. Given the multisectoral nature of CBR, this consultation also needs to involve other major stake-holders including different agencies of United Nations, Governments, Non-Governmental Organizations (NGOs), Organizations of Disabled Persons, etc. as active participants in defining the major issues and goals.

The informal consultation organized at WHO/Geneva on 10 May 2001, has been the first step in bringing the stakeholder involvement.

**Participants & Agenda:** This informal consultation was aimed mainly at UN organizations, representatives of Finland Government and some partner organizations of WHO/DAR. *Annex 1* provides a detailed list of participants.

The aim of the informal consultation was to understand the expectations of the major stakeholders and to define the basic issues related to organization of the international consultation. For linking the discussions to the field experiences of CBR, persons from two field-programmes and a training centre were invited to make brief presentations. *Annex 2* provides a detailed agenda of the consultation.

**Summary of Presentations:**

*Dr. S. Nurshanty* from South Sulawesi Provincial CBR programme in Indonesia and *Dr. M. Kamali*, Deputy for Rehabilitation from Welfare Organization under Ministry of Health in Iran, presented the situation of their respective CBR programmes, including the strengths and problems faced by these programmes. They also made some suggestions for overcoming these problems. *Annex 3 & 4* present a summary of these two presentations.

*Mr. Huib Cornielje*, involved in managing an international training programme for CBR programme managers in the Netherlands, discussed the major issues facing CBR and emphasized the need for taking a critical look at CBR strategies. A summary of this presentation is in *Annex 5*.

*Mr. Kalle Könkkölä* had sent a document for the participants, as he was unable to participate. A copy of this document, "Local consumer oriented rehabilitation and empowerment" is given in *annex 6*.

Finally, *Dr. Sunil Deepak*, illustrated some of the key questions about the organization of the international consultation including – participation of UN

organizations, defining the general goals and methodology, role of NGOs and DPOs, preparatory meetings, total number of participants, criteria for selection of participants and creation of a task force.

**Brain-storming about the organization of the International Consultation in October 2002:** The following proposals were made during the brainstorming discussions:

Aims of the International Consultation: The group proposed that the main goal of the international consultation should be to promote initiation and extension of CBR programmes, which work for mainstreaming and inclusion in the communities. There was also a suggestion to give a wider perspective to consultation on marginalised population groups, even while maintaining a specific focus to disability issues. At the same time, mainstreaming and inclusion of services in existing services and structures is important.

Target groups for the international consultation: It should be governments from developing countries, as well as big international organizations providing resources for supporting CBR like development cooperation agencies from developed countries, EU representative, World Bank representative, international NGOs, international DPOs, etc. At the same time, the national NGOs and CBR field programmes should be invited for presenting their experiences and testimonials about CBR.

Themes to be discussed during the international consultation: A number of themes were suggested as important for the discussions including the following: role of rehabilitation services in promoting empowerment; how to move from small projects or policy documents to full programmes; Impact of CBR on lives of disabled persons; identification of qualitative and quantitative indicators for comparing CBR programmes; scientific resource support for CBR programmes; situation of national policies related to CBR in different countries; inclusion of disabled children in mainstream schools; specific groups of disabled persons for whom CBR programmes do not have any impact on quality of lives; etc.

Structure of the international consultation: Three or four key themes should be identified for discussion in the consultation, devoting about half-day sessions to each theme, through presentation of case-studies and specific experiences, with group discussions and plenary meetings.

Duration of the international consultation: An initial session for formal inauguration in the evening, followed by two and a half days of proper international consultation.

Total participants: Can be between 75 to 100 (hundred is the maximum limit).  
Selection criteria for participants: The main criteria for inviting persons should be their willingness to see CBR programmes in terms of mainstreaming and multisectoral approach. Thus projects/persons dealing with small localized projects, single disability related activities, and those without relevant experience related to the key issues, etc. should be excluded.

Importance of joint action of different UN organizations: It was felt that to have any impact, the joint presence and action of different UN organizations in the initiative was very important.

Sponsorships for the participants: Given the limited number of participants for the meeting, it was felt that different UN organizations can sponsor a small number of Governmental persons from some key countries/CBR programmes, related to their sector of activities. Thus ILO can sponsor a few persons from Ministries of labour and social welfare; UNICEF and UNESCO can sponsor a few persons from education, community activities, women issues ministries; UNHCR can sponsor a few persons working in refugee camps; WHO can sponsor persons from ministries of health and social welfare, as well as from international federations of disabled persons. Those international NGOs which agree with the basic ideas of the international consultation can also sponsor a limited number of persons representing the field experiences, including disabled persons, volunteers, national DPOs, programme managers, etc. Regional organizations like ESCAP and ARI should also be involved. There was also a suggestion to make sure persons from Baltic countries and Russia are also invited, having closer links to Finland.

**Proposals for Future steps:**

- Organization of informal consultations with NGOs; contacts through UN Special Rapporteur, with DPOs for gaining their opinions and ideas regarding the international consultation.
- Identification of themes for case-studies which keep account of richness of existing experiences as well as multi-sectoral nature of CBR. Such case-studies should involve the different stake-holders for maximum impact.
- Creation of a web-site on the international consultation for promoting wider discussions on the major issues and involvement of more persons.
- Creation of a Task-group: In general every one present in the meeting expressed willingness to be part of a task-group for planning the consultation.

## LIST OF PARTICIPANTS

### ILO

Ms Barbara Murray  
Ms. Susan Parker  
Mr. Xavier Coyer

### UNICEF

Ms Gulbadan Habibi

### UNESCO

Ms Sai Vayrynen\*

### UNHCR

Ms. Anne Pedersen

### GOVERNMENT OF FINLAND

Ms Heidi Paatero, Ministry of Social Affairs and Health  
Mr Kalle Könkkölä, The National Council on Disability, Finland\*

### EXPERTS

Dr S. Nurshanty, Indonesia, CBR Programme  
Dr M. Kamali, Iran, CBR Programme  
Mr. Huib Cornielje, Enablement, Netherlands

### WHO/DAR PARTNER ORGANIZATIONS

AIFO – Italy, Dr. Enzo Zecchini\*  
NAD – Norway, Ms Marianne Ziesler  
SHIA – Sweden, Ms. Malin Aldén\*

### WHO

Dr. A. Alwan\*, Director MNC  
Dr E. Pupulin, Coordinator, Disability and Rehabilitation Team (DAR)  
Ms. Eva Sandborg\*, Technical Officer, DAR  
Dr S. Deepak, Technical Officer, DAR

*Note: \* Invited but unable to participate*

**Draft Agenda**  
 Informal Consultation – Preparation for Review of CBR  
 WHO, Geneva, 10 May 2001  
 on  
 International Consultation on “Reviewing CBR” October 2002

10.00	Opening of the Meeting Welcome & Background – <i>Dr E. Pupulin</i>
10.15	Brief Presentations – Major Issues facing CBR programmes S. Sulawesi, Indonesia – <i>Dr S. Nurshanty</i> Iran – <i>Dr M. Kamali</i> Wider perspective – <i>Mr H. Cornielje</i>
11.00	Coffee break
11.20	Brain-storming session International consultation will last two and a half days – what should be its objective? What are the specific areas on which it should focus?
13.00	Lunch break
14.00	Brain-storming session Intermediate steps for arriving at international consultation: some WHO/DAR initiatives (meeting with slum CBR projects in October’01; WHO intercountry meetings in Lebanon, Eritrea & Nicaragua 2001-2002); are there other initiatives with other organizations? – how can these be used for preparing the consultation? Who should be participating in the consultation?
15.30	Coffee break
15.50	Brain-storming session Need for dividing responsibilities and tasks? Creating a Task Group? In what way different partners can contribute to the success of the consultation?
17.00	Conclusions and end of the meeting

## **Summary of Presentation of Dr. Nurshanty South Sulawesi CBR programme, Indonesia**

In this presentation, I am going to provide brief information about the way the CBR programme in South Sulawesi province is organized. After which I shall present the main difficulties faced at different levels by our CBR work and propose some solutions.

The CBR programme in South Sulawesi has been very successful in reaching disabled persons in three districts, with a total population of more than 1 million persons. However, in this presentation, I am not going to look at the successes and accomplishments of the programme. As the aim of this brain-storming meeting is to review the CBR strategies, I have focused my presentation on the problem areas and possible solutions.

Indonesians have a very strong culture of mutual cooperation and this is one of the strengths of the programme. New Government in Indonesia is promoting decentralization, which means more support for the CBR activities. Finally, CBR programme has a committed and motivated team of workers.

*CBR Personnel:* In every district, the CBR programme has a manager and a CBR committee. In each sub-district there is a multi-sectoral team of 4 persons as local supervisors – a nurse, a school teacher, a social worker and a volunteer of women's organization. At the community level, the programme works with community volunteers.

*Disabled persons and their family members:* The programme believes that disabled persons have to play a meaningful role in the activities and they are not the simple recipients of the intervention. The main difficulties are: few disabled persons are involved in the programme as local supervisors or volunteers; many of them are struggling to improve their own livelihood.

*Community participation:* The village CBR committees are supposed to prepare the plan of activities for CBR, to mobilize communities, and to motivate and guide the volunteers. However, not all villages have CBR committees. Some times, the key persons in the committee are not very active and committees don't have any resources for carrying out awareness activities.

*Community volunteers:* Their role is to identify disabled persons, to train the family members, to help in producing simple aids, to refer the disabled persons in case of need and to prepare the reports. However, volunteers have a high drop-out rate and they lack funds for helping them with transport to visit the homes. The training budget for volunteers has not been received and the training materials are not sufficient.

*Mid-level CBR workers:* The local supervisors working at sub-district level need specific training materials; the training material available is limited and the

training they receive is also limited; finally, we need to have trainers at district level as the provincial level trainers can not look after all the needs.

*Provincial and district level CBR teams:* Their role is to develop strategies and program plans, formulate roles of different sectors and coordinate them, plan financial and human resources inputs, and to monitor and supervise the work. However, often the team members are heads of their departments and have high turn over rate and have many other responsibilities.

Generally speaking the human resources involved in the CBR programme need management training. Specific training material about the role of provincial and district CBR managers is lacking.

*Implementing team:* This is the team which has been nominated as over-all responsible for the CBR programme, with a project manager, a secretary, a treasurer and some support staff. Its role is to study the problems, develop program plans, conduct training, monitor the activities and report. However, it is lot of work for few persons, who also have other responsibilities. It would be much easier to develop and follow and develop the CBR programme if there was a separate unit with its own staff and full time responsibility for CBR.

**Presentation by Dr. M. Kamali  
National Plan for CBR in Iran**

*Management:* The management of the rehabilitation affairs of the disabled persons in Iran is a function of the state Welfare Organization that was established in 1980. The First Steps were proceeded to begin the CBR program in Iran in 1990.

*Strategies:* Using existing PHC network to perform and expand the CBR program. Provide accessibility to the rehabilitation services for rural population. Decrease the cost of Rehabilitation services. Provide help for social development. Complete the PHC network with adding CBR as the third level of prevention

*PHC Services in Iran:* The number of the Health House in communities: more than 16000. The number of the Health Workers: more than 24000. The population covered by each Health House : 500 to 1500 people

*Rural PHC centres: Functions:* Monitoring the Health Workers functions. The medical examination and referring to the higher levels if necessary. The intervention on the environment adaptation and the social affairs. Formulating the statically forms and records. *Staff:* Physician, Mid–Level staff.

*CBR role for Health House in communities: Functions:* Identifying the disabled persons. The preliminary testing and referring to the higher levels. Selection of a person from family for training disabled person in home. The intervention in the disabled persons, Social affairs. Organizing the rural CBR committees. Formulating and submitting the statistical reports. Communicating with schools to accept the disabled. *Staff:* Two health workers (Male & Female)

*Main CBR activities:* Training in the house(Using WHO manual), Training out of the home(Kindergarten, Schools...), Short-term vocational training, Ability training, Increase public awareness & change attitude.

*Starting of CBR:* The translation of the CBR books published by WHO. To change and to suit the texts and illustrations on the cultural conditions of the community. The publication and dissemination of the books.

*Coverage of CBR program:* One district (1990); Six district of Six provinces (1995); Twenty district of Fourteen provinces (1996); Twenty one district of Eighteen provinces (2000); Forty district of Twenty Eight provinces (2001).

*Training activities under CBR:* The *PHC Staff* training: The Health Workers: 2 months – intermittently; The Mid-Level Staff: 2 weeks – intermittently; The Physicians 4 days. The *Welfare expert* training: PHC training: 1 month The CBR training: 10 days

Number of trained personnel in CBR project:

City	Population	Number of P.W.D	Number of Village	Trained Personnel				
				Physician	Expert	Technician	Health Worker	Teacher
21	164533	25437	1124	289	11	424	209	105

Rehabilitation situation of people with disabilities:

City	Number of P.W.D	Rehabilitation Situation of P.W.D	
		Number of P.W.D who need Rehabilitation	Number of P.W.D who don't need Rehabilitation
<b>Total</b>	<b>25473</b>	<b>20324</b>	<b>5149</b>

Number of identified people with disabilities and the type of provided Rehabilitation services

Rehabilitation services	Number of needs to Rehabilitation	Number of P.W.D who receive	NO. of P.W.D have not received	Coverage in %
Training in the Family	9565	5768	3797	60
Outside the Family Nursing	3080	1500	1580	49
Referral	6233	5000	1233	80
Provided Rehabilitation Facilities	4170	2106	2069	50
Placement Employment	1688	376	1312	22
Support	5158	2016	3169	38
<b>Total number</b>	<b>29921</b>	<b>16766</b>	<b>13160</b>	<b>----</b>
<b>%</b>	<b>100</b>	<b>56</b>	<b>44</b>	<b>----</b>

*Main Problems:* The Mid-Level persons should be specially trained on the CBR field. Strong coordination between the Ministry of Health and the State Welfare Organization is essential. The need of Health Workers to more training (But CBR does not interact in the training program which is provided by the Ministry of Health). The people's needs and demands are more than the program potentiality (the literacy level has gone up higher than before, the health conditions has been promoted, mass media system have spread and etc.) The CBR has not received its status as a part of the rural development program. The integrated and inclusive education has recently been accepted in the programs of Education Ministry. The sporadic and dispersion of the villages and the their low rate population: 1979 Rural area %65, Urban area %35, 2000 Rural area %30, Urban area % 70. The governmental centred planning and the lack of the people's participation is the decision-making by NGO. The integration between CBR and PHC has not happened and some resistance exists.

**Presentation by Huib Cornielje**  
Major Issues facing CBR Programmes:  
**The wider perspectives**

Is CBR a Priority?: In the South certainly not... (and in the West...?); water, food, education etc are of greater importance; largely responsibility of NGO sector (as it was previously in the West) and this is maybe not wrong at all since this is the sector with most expertise; what arguments do we have to get disability higher on the political agenda?; Human rights perspective? Certainly successful in South Africa but will it work in Pakistan?

Economic reasons e.g. Investing in Rehabilitation? There are hardly any arguments to bring in. Even large micro-credit programmes such as BRAC and Grameen Bank in Bangladesh regard PWDs as high financial risks and have to admit that less than 1 Percent of their beneficiaries are disabled... Yet, in order to really rehabilitate disabled people income seems to be a very strong success factor...

Emerging demographic and epidemiological changes (besides continued 'old' reasons...)? Do governments acknowledge this and do they pro-actively invest in appropriate solutions? I am not yet convinced...

Feasibility of CBR: is CBR the most appropriate way of rehabilitating disabled people; is CBR the best way to integrate PWDs in society? is CBR the most cost-effective way? Effectiveness is probably low outside highly subsidized pilot schemes...; Is CBR not all too often a second rate poor services – what evidence do we have it isn't? What about type of disabilities? Polio in the 20<sup>th</sup> century was easy to deal with, but CP among other profound and multiple and mental and spiritual disabilities which we see increasingly ...in the 21<sup>st</sup> century is another game altogether...;

What is behind it?: Better perinatal care has improved survival chances of profoundly handicapped children; Increased life expectancy results in growing older population and increased chronic conditions with subsequent disabilities; Ongoing and increased violence and accidents result also contributes largely to prevalence of disability; Substance abuse in many forms promoted by media and multinationals resulting in mental-spiritual disabilities

Yet, overall we need to admit that: In many situations the prevalence of serious disability is actually low (much lower than we thought or were told...); local communities have own traditional coping mechanism. CBR may be an additional instrument to deal with problems.

Questions relating to appropriateness of CBR: are there resources available to tackle multiple and profound problems? Mothers, but...; Is CBR able to tackle these issues?

Human Rights: Does the South wait for individualistic Western Disability Rights models? As fast as they move into such paradigms as fast as the mutual, social

and neighbourly behaviour will disappear... (which the CBR movement rightfully considers to be of great importance); Does the mother with a disabled child not 'just' want the best service available for her child? So, let us not abandon service delivery...; Selective versus comprehensive (development?!) approaches; Individual-medical-service models versus? socio-political models or DO THESE MODELS COMPLEMENT EACH OTHER?; Services as requirement for 'empowerment'? and empowerment resulting in demands for better access to schools, work etc. Who will benefit from social empowerment models...? The wealthy jet-setting urban middle-class disabled person or the great masses in rural areas and urban slums? There is a lot of RHETORICS. Let us be careful and get realistic. A special school is sometimes the best solution! Admission of a child with a profound and complex behavioural handicap in an institute is sometimes the best solution for the child and family!

Globalisation and uniformity (versus small-scale): isn't this in contrast with the notion of having respect for differences in cultures, but some frameworks leaving enough space for local solutions is fine. Scaling – up: if CBR is to have any larger impact it seem to be needed...but needs to be accompanied by strengthening of rehabilitation capacities at higher levels as well; what is socio-economic and political gain for the South?; Yet, that what works at local level with hard work (and serving leadership) doesn't work in government settings with at best mediocre public servants (who goes that extra mile?) The strengths of these small programmes may easily become their weakness as well in terms of sustainability.

Organisation: Vertical versus horizontal programmes – community rehabilitation workers (CRWs) are often working parallel to existing services and often can only provide partial solutions which may turn out to be wrong solutions & Need for good referral to higher tiers-levels: it is impossible to organize rehabilitation solemnly at community levels; Selective versus comprehensive; Feasibility of working with volunteers; Problems with supervision; Link with DPOs.

Evaluation and indicators: we are obliged to do so... since there is quite some rhetoric on CBR (e.g. being the best, unique, most appropriate, cheapest...); if we don't do it CBR may be dead within the next 20 years...; focus on quality of the provided care and services will form a major step forwards towards policy. If we can prove it is the best, most appropriate efficient approach we have a point! But what evidence do we have so far? So need for outcome indicators.

Finances: unless disability is seen as priority in the eyes of politicians and policy makers no substantial financial means will become available; without financial means limited CBR development.

*It is up to CBR programmes to come forward with criteria of quality, efficiency and affordability and prove that CBR is the proper answer to the rehabilitation needs of communities.*

**LOCAL CONSUMER ORIENTED REHABILITATION AND  
EMPOWERMENT (LoCoRE)**

*Presented by Mr. Kalle Könkköölä*

Rehabilitation and empowerment of disabled people done by disabled people. The idea is partly to go back to the roots of CBR and partly go beyond that. This means local rehabilitation activities, which are based on local resources, and activities. Empowerment is also an elementary part which gives disabled people themselves strength and capability to take over their own lives. One basic method is peer support and counselling.

It is important that disabled people do the actual fieldwork themselves. For that purpose one of the first tasks is to mobilize disabled people to this work and give them education for that purpose. This also creates work possibilities. Disabled people who are to become fieldworkers need a six-month training and after that a year of practice on the job. The training shall include basic rehabilitation training and also some other elements. Peer counselling skills are vital important. The philosophy of independent living and modern disability movement is basic elements. Also the history of disabled people in own country and world which is important. The idea to encourage and motivate disabled people is elementary.

The method of studying must be based on teamwork and with disabled teachers as much as possible. People have to learn to understand that disabled people can do everything. The approach must be cross-disability. People with different disabilities learn to know other disabilities. Naturally people can also specialize in their own disability, but they must have basic understanding of other disabilities and problems related to them.

Those disabled people who are managing these activities need longer education but they should also participate this LoCoRE training course. We should approach funders to start a pilot project in this. First we have to create an international planning group with experienced disabled people. This group could have a weeklong planning session.

After that we could have the training and have people from three different countries participating. The planning group could some time plan a pilot project for three countries for three years. This workshop could last five days. If for ex. we could have a training of 48 (3 x 16) people in one year we could start working in 24 villages.

The financing for this activity could come either from governmental funder or from governmental funder and development bank. One plan to start this activity is in Asia/Pacific and second area is Latin America. Project needs an overall co-ordinator and regionally three motivated co-ordinators and secretary and 48 fieldworkers. The training needs staff of its own but could probably be done with some existing educational institutes together with DPI.

Kalle Könkkölä