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International Consultation to Review Community-Based Rehabilitation (CBR)

Organized by
World Health Organization

In collaboration with United Nations Organizations,
Non-Governmental Organizations and
Disabled People's Organizations

Hosted by the Government of Finland

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Executive Summary

The World Health Organization (WHO), in collaboration with other United Nations Organizations, has promoted community-based rehabilitation (CBR) for over two decades. Although CBR programmes have been initiated in many countries, the people who work in the programmes have never had the opportunity to come together at the international level to discuss what they are doing and how they can continue to use CBR to promote the rights of all people with disabilities. The Government of Finland kindly agreed to host and support an international review of CBR. WHO invited stakeholders, including other UN agencies, international non-governmental organizations, international organizations of disabled people, and representatives of governments. Many of the stakeholders supported participants who are involved in CBR programmes. The International Consultation to Review Community-Based Rehabilitation was held in Helsinki from 25 to 28 May 2003.

From 2000 to 2002, WHO sponsored a series of meetings on CBR. The recommendations from those meetings identified four major topics relevant to strengthening CBR. These were the topics that guided the discussions during the review of CBR: 1) Community involvement and ownership; 2) Multisectoral collaboration in CBR, 3) The role of Disabled People's Organizations in CBR; and 4) Scaling up of CBR programmes. In addition, the participants discussed the evolution of CBR from a model that was often viewed as medical to one that promotes the rights of people with disabilities.

Recommendations from the international review of CBR were prepared by specific groups who addressed their own constituencies:

- Disabled People's Organizations (DPOs) Working Group: Recommendations to DPOs;
- Governmental Working Group: Recommendations to Governments;
- Non-Governmental Organizations (NGOs) Working Group: Recommendations to International and Local NGOs, Universities, and Professionals;
- United Nations Agencies Working Group: Recommendations to UN Agencies.

Consultation participants re-affirmed that CBR is a useful strategy to promote human rights, to provide services, and to ensure equal opportunities for all people with disabilities. Highlights from the recommendations include the following:

- All stakeholders in CBR should work to ensure the human rights of all people with disabilities;
- Government policy and support are essential for the development of CBR programmes, including policies that support the rights of people with disabilities;
- Multi-sectoral collaboration is essential to CBR, including co-ordination between community and referral services, and among the various referral services;
- DPOs have essential roles in educating and training people with disabilities regarding their rights, in advocating for a response to the needs of disabled people, and in collaborating with all partners to implement and monitor CBR activities;
- UN agencies, international and local NGOs should collaborate with governments in the promotion of CBR as a strategy for the inclusion of people with disabilities in all programmes for development and poverty reduction.

Acronyms

AIFO……Italian Friends of Raoul Follereau

CBR…….Community-Based Rehabilitation

DAR…….Disability and Rehabilitation Team (at WHO)

DPO…….Disabled People's Organization

EFA……..Education for All

HFA……..Health for All

GEA……..Global Employment Agenda

ILO…….International Labour Organization

INGO……...International Non-Governmental Organization

MDG……...Millennium Development Goals

NEPAD……New Partnership for Africa's Development

NGO……Non-Governmental Organization

PHC…….Primary Health Care

PRSP……Poverty Reduction Strategy Paper

UN…….United Nations

UNESCO….United Nations Education, Scientific and Cultural Organization

WHO……...World Health Organization

YEN……Youth Employment Network

Introduction

The United Nations declared 1981 as the International Year of Disabled Persons, followed by the International Decade of Disabled Persons from 1983 to 1992. Since the early 1980s people with disabilities have developed and strengthened their organizations, and they have achieved increased opportunities for education and employment. However, much remains to be done to ensure equal opportunities for all disabled people. An estimated 600 million people experience disabilities, most of them in poor countries where basic services and survival are still a challenge.

Community-based rehabilitation (CBR) developed as a response to the need to reach people with disabilities at the community level. In its early days, CBR was often associated with the health sector because many programs started within that sector and used primary health care workers as the liaisons with disabled people and their families. The evolution of CBR is reflected in the definition given in a joint statement by ILO, UNESCO and WHO in 2002: 'CBR is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities.'

CBR has been used in many countries during the past twenty years, but there had never been an opportunity for those who implemented programmes to come together and review what they had done and how they might continue to use CBR as a strategy to promote the rights and opportunities for all people with disabilities. From 2000 to 2002, WHO organised a series of meetings to identify key issues concerning the work of CBR programmes. During these meetings it was agreed that an international consultation should be held to review CBR. WHO invited all stakeholders, including other UN agencies, international non-governmental organizations, international organizations of disabled people, and representatives of governments. Many stakeholders agreed to support participants who are involved in CBR programmes.

On request, the Government of Finland agreed to host and support an international review. The International Consultation on Reviewing Community-based Rehabilitation was held in Helsinki from 25 to 28 May 2003.

Prior to the Consultation, background papers were submitted to WHO and the Finnish Organizing Committee. The Italian Friends of Raoul Follereau (AIFO) collaborated with WHO to make the background papers available on the WHO/DAR web site. Based on the papers, a theme paper was prepared as background for the meeting. All papers are available on the web site: http://www.who.int/ncd/disability

Proceedings of the Conference

The proceedings of the Consultation focused on discussions of issues relevant to the strengthening of CBR programmes. Each discussion began with papers presented by participants who are actively engaged in implementing or supporting CBR programmes. The final task of the participants from the different stakeholders was to prepare recommendations to their respective constituencies on how to improve their own performance in the joint effort to strengthen CBR. One hundred and ten people, representing the various stakeholders in CBR, participated in the conference. Participants came from all regions of the world: Africa, Asia, Europe, Middle East, North and Latin America.

(See Agenda and List of Participants at http://www.who.int/ncd/disability)

The opening ceremony of the International Consultation took place on 25 May at the Kiasma Museum of Contemporary Art in Helsinki. Dr Enrico Pupulin, Coordinator of the Disability and Rehabilitation Team at WHO opened the meeting by thanking the Government of Finland and the Organizing Committee, and welcoming the guests. He then introduced Dr. Liisa Hyssälä, Minister of Health and Social Services, who welcomed the participants. Ms Marja-Liisa Niemi, Counselor on Education, Ministry of Education, also welcomed the participants and provided background on the interest of the Government of Finland in the Consultation on CBR. Mr. Kalle Könkkölä, Chair of The Threshold, welcomed everyone to Finland and expressed his gratitude to the Government of Finland for supporting the participation of the Disabled People's Organizations (DPOs). Participants were given the opportunity to have a guided tour of the museum prior to dinner at the museum.

The Consultation format on 26 and 27 May consisted of presentations followed by discussions. On 26 May Ms R. Viitala, Deputy Director-General, Ministry of Social Affairs and Health, Finland; Ms Barbara Murray, ILO; and Mr R.K. Khalfan, Disabled People's International chaired the meeting. Dr Pupulin began the plenary session by providing the background and the aim of the Consultation. The first topic, Community Involvement and Ownership, was then introduced and examples were presented. This format was followed for each of the other topics: Multisectoral Collaboration, the Role of DPOs and Scaling Up CBR. (See the Agenda on the web site for the titles of all presentations and the names of all presenters.) In the afternoon session, Multisectoral Collaboration was discussed. Each discussion group was composed of representatives from all of the various stakeholders.

On 27 May, Mr L. Odegaard, Norwegian Association of the Disabled; Mr K. Eklindh, UNESCO; and Ms R. Sandhu, Ministry of Social Justice and Empowerment, India chaired the meeting. The summary of the first discussion was presented. Because the report was long, there was a consensus that further summaries of the discussions would be given to the chair and rapporteurs of each group so that they could verify that the opinions of their groups were adequately represented. The topics for discussion on the second day were The Role of DPOs and Scaling Up CBR.

On 28 May, Ms J. Heumann, the World Bank; Ms K. Nordstrom, World Blind Union; and Ms S. Matsebula, Office on the Status of Disabled Persons, South Africa chaired the meeting. For the discussions, the composition of the groups changed. Each group consisted of one of the CBR stakeholders, i.e., DPOs, non-governmental organizations (NGOs), governments, or UN agencies. Each group formulated recommendations for actions that stakeholders belonging to its group could take to strengthen CBR programmes. The rapporteurs for each group presented the recommendations to the participants.

The International Consultation on Reviewing CBR was closed on 28 May by Ms Ritva Jolkkonen, Director General, Department for Development Policy, Ministry for Foreign Affairs.

Summary of the Discussions

As noted above, each of the six discussion groups had four topics to discuss. For each topic, the reports from the six groups were combined to form the summaries presented below. For the discussions, WHO defined 'community' as the smallest administrative area where people live.

Some issues were addressed under more than one of the topics, particularly issues related to the concept of CBR and to the activities of DPOs. To avoid repeated presentation of these issues, a summary of the comments on CBR are presented separately. Major points about the DPOs are also presented, but they are further elaborated under the topic, the role of DPOs in CBR.

Community-Based Rehabilitation

The definition of CBR in the ILO-UNESCO-WHO Joint Position Paper, 2002, was accepted by the participants: 'CBR is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities.' This agreement reflected the consensus that CBR has evolved from a model that was often perceived only as medical to a more comprehensive model, and that CBR now has a major focus on human rights. Hence, CBR is a strategy for achieving the rights of people with disabilities within the context of their communities and societies. It is also a strategy relevant to community development and to national strategies for poverty reduction. CBR should be an integral component of these national programmes and strategies.

Because CBR has evolved into a strategy focused on the human rights of people with disabilities, the full participation of people with disabilities is essential. There was also consensus on the need for a multisectoral approach . The essential roles of ministries of social welfare, health, education and labour were noted repeatedly.

Participants recognized that there are many models of CBR, each unique to its own country. However, it was generally accepted that government involvement is essential in order to ensure adequate support through policy and legislation, and to ensure strengthening of referral services. All shareholders must collaborate for the co-ordination of services, but it is useful if government takes a leading role for this.

Some participants expressed concern with the use of the word 'rehabilitation' because it is time limited and CBR is ongoing. One suggestion was to use 'rights' to emphasise the concern with human rights. Other participants felt that it has taken a long time for governments, agencies and donors to understand the significance of community-based rehabilitation, so a change of name could create confusion and delay the implementation of CBR strategies. It was also pointed out that "CBR" has become part of the national rehabilitation strategies in many countries and a change of name would also create confusion in such situations. There was no consensus regarding recommendations for changing the name of CBR.

Consultation participants re-affirmed that CBR is a useful strategy to promote human rights, to provide services, and to ensure equal opportunities for all people with disabilities.

Disabled People's Organizations

Over the past 20 years DPOs have become increasingly capable of taking leadership roles in CBR, to the extent that people with disabilities can initiate programmes and set priorities for CBR activities. However, DPOs and communities cannot work alone. Government participation is essential to the effectiveness of a CBR programme. Local and international NGOs make significant contributions through the provision of services, technical information and funding. DPOs recognize that all stakeholders can work in collaboration with each other to maximise the

use of resources, so DPOs can work with governments to promote the co-ordination that is required for successful CBR programmes.

Within many of the discussion groups, there was commentary about the effectiveness of cross-disability and single disability organizations. It was clear that each has a role to play, and that collaboration among all organizations is essential in order to promote the rights of all people with disabilities. The pros and cons of the two types of organizations are presented in the summary of the third discussion.

In many countries DPOs strive to increase their membership. In countries where there is not full access to technical assistance, such as machines for Braille, or there is not adequate support for communication, such as sign language interpreters, people who are blind or deaf may not be effective participants in DPOs. In many countries, people with disabilities due to psychiatric conditions or intellectual impairments are not represented in umbrella organizations of disabled people. These individuals, as well as children, are often represented by family members, or are not represented at all. Adults with psychiatric conditions are eager to participate with other disabled people, but they have not found it easy to become full participants in DPOs. Adults with intellectual impairments, and children with all types of impairments, have the right to express their own needs and to participate in decision-making on issues that concerns them. DPOs are aware of the situation and are committed to expanding their memberships and to better representing all people with disabilities.

DPOs are also trying to increase their memberships in all areas of their countries, and in all socio-economic groups. Disabled people in rural areas, as well as in poor urban areas, are not well represented in DPOs. The issue of inclusion in DPOs is also presented under the third discussion summary.

There was agreement that in all countries DPOs need an on-going source of support for capacity-building and for their work, but the source will vary among countries. Examples include regular support from government; a special fund or project run by DPOs, or by an organization that supports DPOs; and annual fund raising.

1. Community Involvement and Ownership

Awareness Raising and Commitment of Resources

Creating awareness about CBR requires activities focused on both the community and the decision-makers at higher levels. Awareness raising cannot be general, but must be appropriate to the targeted group. It is necessary to communicate in a manner compatible with the culture, which includes the use of appropriate language.

Within the community there are different target groups – political, religious, etc. – and each should be approached with a different strategy. People need to be aware of the benefits of CBR. There is a need to project successful role models of disabled persons, as well as success stories of other communities that started CBR. This can inspire a community to want to start it.

To raise awareness, the community could participate in a needs assessment to identify priority issues. Also, people with disabilities should not wait for specific discussions of disability, but

should get involved in discussions that concern other groups in the community, e.g., disabled women can get involved in women's issues. This raises awareness.

At the community level, awareness raising can use cultural events, such as sports, or religious and cultural activities. More use could also be made of regional Decades and international events, such as the International Day of Disabled Persons.

At national level, planners are not always knowledgeable about disability issues. Also, the concept of CBR is not clear to many people, including governments and funding agencies. It is necessary to provide a clear concept of what CBR is and what can be accomplished. It is important to explain that CBR is not just about disabled persons, and that the activities will help the entire community.

Ministries of social welfare, health, education, labour and information, as well as NGOs, must be involved in awareness raising. It is important to involve service providers, so as to improve the access of disabled people to services. It is also important to use the media.

Creating awareness of CBR does not ensure that community and government resources will be allocated to addressing the concerns of people with disabilities. To ensure that funds are provided, people with disabilities can become well informed about the local and national sources for funding, and thus be able to seek funds in an effective manner. This requires education to develop the skills required to prepare proposals and to convince donors that the funds will be used to benefit people with disabilities.

It is also important that CBR assures the participation of all people who have various types of disabilities. Some groups are still marginalized. In some countries it may be people who are deaf. In many countries it is people with psychiatric or intellectual disabilities, as well as people with AIDS. People with disabilities can also consider working with other groups of marginalized people, such as the urban poor.

The issue of human rights can be used to ensure that resources are allocated to people with disabilities. There are relevant human rights conventions that apply to all citizens and that are not used effectively to argue for the rights of girls, boys, women and men with disabilities. Governments have signed human rights conventions and they must protect the rights of all of their citizens. DPOs can prepare shadow reports regarding national follow-up on the implementation of human rights instruments.

Too often there are policies on paper that indicate that the rights of people with disabilities will be observed, but it does not happen in practice. Usually this occurs because there is no opportunity for people with disabilities to challenge their lack of rights or access in the courts. This situation is further evidence of the need for people with disabilities to be better educated and better prepared to defend their rights.

Funding agencies may say that they fund programs, such as housing, for all people. But they do not provide funds to people with disabilities. National policies should be established that require all funding agencies to include disabled people in all projects or programs. For example, funding for poverty reduction should always include funds for meeting the needs of people with disabilities, who are among the poorest.

Awareness raising can be linked with efforts to lobby for the development and implementation of disability policies. Participants noted that finding the resources for these activities may be difficult.

Empowering Communities for Planning, Implementing and Evaluating CBR

A structure is needed for CBR, and for the delivery of necessary services. However, the ownership belongs to the community. Capacity building of communities, including people with disabilities, is needed so that they take an active role. Implementing agencies from outside should be seen only as catalysts. A CBR programme has participation of the community in all activities of planning, implementation, monitoring and evaluation, so it is a gradual process. This should be kept in mind at the time of strategic planning.

CBR does not work if it is 'given' to communities. Communities must want to have CBR, and then they can become empowered by building on what they already have and what they want to accomplish. External donors should not import everything, but should involve the community and its resources to create ownership.

The role of volunteers varies among CBR programmes. Volunteers may be seen as part of 'idealised' communities. Volunteers have a fast turn over, but with all of their limitations, the volunteers are very important for community involvement and ownership and should be encouraged. Volunteers help to create awareness, and can also increase sustainability. However, programmes cannot run only with volunteers. Volunteers may sometimes need reimbursement for their transport, or they may be given a small compensation.

While empowering communities for CBR it is necessary to remember that communities are not uniform, but vary by socio-economic status, ethnic diversity, language, etc., so participation may not be equal. It is also important to recognize that it is not practical to have all decision-making at the community level. The bottom-up process at the community level needs to be matched with a top-down process to support community efforts.

The changes that have occurred in CBR over the past twenty years have included an increased emphasis on the empowerment of people with disabilities. Governments or NGOs used to speak for people with disabilities, but now, in many countries, DPOs speak for themselves. Control of the funds is one means to empowerment, so people with disabilities must take part in the decision-making regarding the use of funds.

Empowerment means deciding for oneself, but it is also important to have the resources to implement decisions. Empowerment of DPOs is important, but it is also important for DPOs to educate the community about the rights of each disabled person to make decisions about his or her life. Some people with disabilities seek economic independence. Some may seek the capacity for independent living, while others may have different goals. Denying people with disabilities their human rights is a clear obstacle to empowerment. Obvious violations of human rights occur, for example, when people with psychiatric conditions are prevented from having a choice about their treatments, or people with movement limitations are denied access due to physical barriers.

Empowerment is a very broad concept and includes social, political and cultural aspects. A dialogue between service providers and users is needed for the empowerment of DPOs and of all individuals with disabilities.

Decentralising Government CBR Programmes

Government must be involved in CBR. However, the degree of involvement varies among countries. The central level of government must be willing to empower the community in order for CBR to function. Some countries are more willing than others to encourage community action. The degree of decentralisation within the government ministries also varies among countries.

If a centralised government decentralises, there can be chaos for a period of time. People in the community are not accustomed to taking responsibility. They do not know how to create awareness of issues, and they do not know how to lobby for their interests. All people need to be educated in order to manage in a decentralised environment. People have to learn how to take responsibility, how to negotiate conflict, and how to manage finances, such as loans.

Even with decentralised governments, CBR programmes may not have the flexibility they need in order to develop. It may be necessary to create societies, or other types of legal entities, that can fund raise for activities at the community level. The creation of disability interest groups at community level is very important. Such groups could be composed of DPOs, parents, teachers and health care workers.

Governments that give responsibility to the district level may not trust the capabilities of people with disabilities to run programmes at the district level. DPOs have to prove to governments that they can work at all levels, and that they can provide services effectively.

CBR in Community Development

CBR can be integrated into community development. This can ensure that there are inclusive programmes rather than seclusion or isolation of disabled people. It can also ensure that people with disabilities experience the same quality of life as others in the community.

CBR can link with existing programmes in order to develop with them. The primary health care (PHC) system and the local schools can be very important for promoting and supporting CBR. General development programmes, like poverty reduction programmes, water and sanitation programmes, etc. can also address disability issues. Hence, it is important for people with disabilities to work with health, education and other relevant programmes to promote appropriate services.

CBR should be seen as a cross-cutting issue for promoting disability awareness in all the programmes. Some specific disability issues may require specific programmes or activities, but wherever possible, the goal should be inclusion.

International organizations, like the UN agencies, the World Bank, and donor organizations can use disability as a cross-cutting issue. The departments of the international agencies that work directly with people with disabilities have the responsibility to inform other departments about the concerns of disabled people, and to promote the inclusion of disability issues in all development programmes.

International NGOs can help to develop the capacity of DPOs to participate in community development. For example, DPOs could strengthen their capacities to lobby, influence policy and legislation, and influence the political agenda. It is also important for people with disabilities to make broad alliances and involve others, and not to feel that CBR belongs only to them.

2. Multisectoral Collaboration in CBR

Participation of Ministries

Each country should have a national policy that addresses disability issues. There should be a 'political will' at all levels and within all ministries so that each promotes the implementation of the national disability policy, and actively contributes to the development of CBR. Disabled persons can take an active and leading role in advocating for policy formulation and implementation through the different ministries.

Some countries have found that a national level council or committee of ministries, donors, and NGOs, particularly DPOs, is needed for co-ordination of a CBR programme. Such a council could ensure that policies are implemented, and that legislation is monitored. The council could also co-ordinate the raising and allocation of funds for CBR. A council of all partners in CBR should also ensure that all people with disabilities are included, particularly people with psychiatric or intellectual disabilities, who are traditionally left out of programmes. Some countries established national co-ordination committees for the Standard Rules. Such committees could also ensure an integrated approach to the implementation of CBR programmes. A separate budget for ensuring the functioning of the co-ordination council or committee is necessary.

However, such a council may have shortcomings. The presence of donors in the co-ordination committee can lead to a conflict of interest. Or, representatives of the ministries may not have any powers, so the council does not work. Placing the co-ordination at a high level, e.g., in the office of the prime-minister or president, may be more effective in promoting collaboration, and may also be very important in co-ordinating cross-cutting issues like women, children, and disabilities.

For multisectoral participation, a lead agency is needed, but each ministry and NGO can have a clear plan of action. All stakeholders should view CBR as a strategy, or an approach, and not as a project. Projects are short-lived and often are not integrated into ongoing programmes. All stakeholders must understand their roles and what they need to do. DPOs must collaborate among themselves as well as with the other agencies involved. Networks where ideas can be shared are important.

Historically, disability was seen as a social welfare issue. However, very often the ministry for social welfare is seen as very 'weak'. Initially, the ministry of health was thought to be the best ministry to start CBR because there was a network reaching to the community through PHC. However, this approach was associated with the medical model, so some countries prefer to have another ministry take the leading role. Some countries believe that primary responsibility for CBR should be shifted to a planning or development ministry, which looks at all aspects of development and is able to co-ordinate the budget of other ministries. This brings the wider perspective and collaboration that are needed. This also works well at the grass roots level, where the development of all sectors, including health and social welfare, is relevant.

Other important ministries include the one for education, which can promote inclusive education. Income generating projects for people with disabilities are essential, so the ministries for employment, commerce and trade are important partners in a CBR programme. As noted in previous discussions, poverty reduction programmes may be important programmes for CBR to link with because they address issues of concern to people with disabilities, and they have a strong participatory approach.

In addition to the need for co-ordination among the various sectors that support CBR, there is also a need for co-ordination within each sector. Sometimes the lack of co-ordination within a particular ministry results in contradictions among programmes implemented in different parts of the country. For example, in one part of the country inclusive education may be promoted, while in another area of the country special schools are promoted. This poses difficulties for CBR programmes.

Collaboration among CBR programmes in different countries will allow the programmes to benefit from the experiences of others. A south to south strategy for collaboration would be useful.

Ensuring an Integrated Approach by Local and International NGOs

International and local non-governmental organizations (INGOs and NGOs) that work with CBR should be accountable to a co-ordinating council or committee, preferably within the government. Different countries may have different requirements for allowing INGOs and NGOs to work. National guidelines and strategies are important so that all INGOs and NGOs follow them and make sure that they do not promote completely contradictory strategies. Different organizations may be involved in different activities related to disabled persons, so co-ordination among them is very important to avoid repetition and to fill gaps. Organizations are often in competition among themselves, and although they talk about co-ordination of ministries, they do not co-ordinate themselves and they carry out parallel activities. In the process of competing among themselves, they waste resources. INGOs need to be clearly co-ordinated by partner countries that give a strong sense of direction.

Donor agencies form a separate group that needs careful consideration. Donors strongly affect the CBR programme, and often they do not co-ordinate their work. This group should also be co-ordinated by the recipient government, and in addition, should take the initiative to find out what is needed and to co-ordinate with other donors.

If there is a national co-ordinating council or committee for CBR, and if it is effective, it will contribute to the co-ordination of the local and international NGOs, as well as to the co-ordination of the work of the ministries. DPOs can act as watch dogs to make sure that all agencies work properly.

DPOs are a very important part of the local NGOs, so DPOs can play a leading role in promoting the human rights approach and advocacy within all organizations. DPOs can also lobby INGOs to make sure that all development projects include disability issues, with special emphasis on the inclusion of disabled women.

DPOs can take on a role as service-providers. Some INGOs have assisted national level DPOs in this role because the INGOs believe that providing services is a good example of how DPOs can help all disabled persons in their own countries.

Strategy for Co-ordination Among the Stakeholders

Government policy on disability should be the basis for co-ordinating the partners for CBR. For example, the policy of the government should clearly indicate the priority to be given to strengthening programs for inclusion and to developing institutions that meet special needs. Government policy should guide the NGOs just as it guides the ministries. Government could encourage NGOs to develop programmes that are consistent with government policy and the CBR approach.

A common, shared goal is needed for effective co-ordination of CBR stakeholders. The mechanisms of collaboration can be made transparent, and the responsibilities of each can be clearly spelled out. Problems are created by lack of trust and by difficulties in sharing resources, skills and ideas with others, etc. These problems can be recognized and addressed.

Sharing of information is essential for good co-ordination of a CBR programme. Especially in larger countries, it would be useful to have a central location where information is available about the work of all local and international NGOs, as well as the ministries that contribute to the CBR programme. In all countries, periodic meetings of the partners would also promote communication and collaboration. In all CBR programs, the partners should take some responsibility for co-ordinating among themselves.

Resources can be allocated to support the co-ordination and communication. All stakeholders can contribute to the costs of co-ordination.

Implementation of The Standard Rules

There are countries where The Standard Rules on the Equalization of Opportunities for Persons with Disabilities are not implemented. Some governments appear to be unaware of the Standard Rules. Many people with disabilities feel that a convention on the rights of people with disabilities is needed because governments take conventions more seriously than documents such as the Standard Rules. Others point out that the Standard Rules are a valid instrument that can and should be used in all countries. DPOs need to lobby if they want action with regard to these Rules. CBR programmes can provide information about the Standard Rules and can increase awareness of them.

WHO sent countries a questionnaire about the impact of the four Standard Rules related to health issues. Initiatives like this are very important and make the governments realise that they have to do more to implement the Rules. The Standard Rules can also be used to prepare country reports on the situation of people with disabilities.

Compliance with the Standard Rules can be measured by examining compliance with other conventions relevant to disability. DPOs and CBR programmes should use other instruments, such as the Conventions on Human Rights and on the Rights of the Child, and the ILO Convention No. 159 on national policy for employment of people with disabilities.

The United Nations has published a study on the current use and future potential of the U.N. human rights instruments in the field of disability. The document, Human Rights and Disability, was recommended to all participants. (<http://www.un.org/Pubs/sales.htm>)

Aside from lack of awareness, the implementation of the Standard Rules has also been affected by the lack of technical and financial support that is needed. This lack of support has limited the impact of the Rules in many countries.

UNDP is the main co-ordinator and implementer of country programmes aimed at development, but it does not consistently support disability issues. UNDP should support the implementation of UN conventions and Rules relevant to disability. UNDP could also add a disability perspective to its human development index.

3. The Role of Disabled People's Organizations in CBR

Participation of People with Disabilities

Participation requires access. Accessibility, participation and inclusion are matters of human rights. These issues include physical, sensorial and economic barriers. There are barriers and solutions at the macro and micro levels that must be addressed. The environment must be free of physical barriers for people with mobility difficulties. Information must be accessible for people with visual, hearing or intellectual difficulties. Economic barriers must be recognized and addressed through programs that promote equalization of opportunities. Attitudinal barriers must also be removed for all people with disabilities. Legislation for facilitating access, participation and inclusion is important.

Issues of access and participation can be analysed in terms of policies, legislation, raising awareness and practical aspects. For example, there are goals like Education for All, but there is no effort to promote the use of Braille materials. Communication for people who are blind is often limited because information is not provided in Braille. In addition, accommodations are not made for people with low vision, who also need to be considered in situations like exams, when large print is needed, but not provided. There is a lack of awareness training for teachers, and a poor understanding of the issues faced by disabled children on the part of other students. A program such as Child-to-Child can be very useful, but such programs are rarely implemented except as pilot projects. Advocacy and lobbying with governments on these issues are essential.

When governments do discuss accessibility issues, they often forget to involve disabled people in the discussions. At the same time, people with disabilities and DPOs do not have the capability for advocacy and lobbying for these issues. Capacity building of DPOs is needed. Sometimes people with disabilities lack the skills and the courage they need to promote their own empowerment. They need to know that they have rights and they need encouragement to participate.

For people with disabilities to get support and to participate, specific services have to be paid for, such as sign language interpreters, Braille equipment, guides, and transport. Lack of transport is a significant difficulty in the development of DPOs. Lack of accessible information and lack of training are other problems. Planning within CBR should include budgeting for such services. An essential role of DPOs is to educate others about the need to plan for the services and for the budget to pay for them.

DPOs at national level would benefit from communicating with each other and planning together. It is important for DPOs to motivate people to get involved, and also to train people with disabilities who have not been participating in activities to promote access and equal rights. DPOs should train people throughout the country, especially in rural areas, where people with disabilities may not be well informed about issues that affect their lives. Special efforts could be made to reach under-represented groups, such as people with psychiatric or intellectual disabilities or people with AIDs. Special efforts may also be needed to involve women and children with disabilities.

Who is responsible to empower people with disabilities? Government should provide training for leadership so that DPOs can develop. CBR programmes have taken responsibility for developing DPOs, so as programmes expand, DPOs can take leadership roles. CBR has also promoted the provision of appropriate technology, such as white canes or appropriate wheel chairs. To support people who are deaf, CBR programmes have promoted visual teaching aids and the teaching of sign language for parents, care-givers and teachers.

CBR provides an opportunity to show the society and the community how inaccessible they actually are. This gives the society and communities a chance to do something about the barriers to participation. However, participation is not enough. People with disabilities need *inclusion*.

Access to CBR Programmes for All People with Disabilities

In theory, CBR is for all people with disabilities, but if resources are limited, only certain groups may receive its benefit. The role of DPOs is crucial for CBR programmes because the DPOs can explain to communities what the needs and priorities are for all people with disabilities. However, DPOs do not always represent all people with disabilities.

Many DPOs that form single disability groups have themselves started CBR programmes. For such programmes, these groups may need to broaden their services to include all different groups of disabled persons. For example, if an organization of deaf persons has initiated CBR in a village, the organization must know how to also provide services to other people with disabilities, so the members need capacity building. There are many examples where this is already happening. In some countries, a cross-disability organization and a single disability organization work together to initiate a CBR programme. Within the DPOs themselves there can be less attention paid to certain groups, e.g., people with multiple disabilities, psychiatric conditions, or intellectual impairments.

Both single and cross-disability organizations of disabled people at national and international levels have expertise in advocacy. At national level, DPOs have also developed expertise in collaborating with governments and other NGOs to promote, and sometimes to provide, support services for their constituents.

The roles of different types of DPOs could be clarified so that each can contribute to CBR programs and to the inclusion of all people with disabilities. Some believe that single disability organizations are better prepared to represent disabled persons with specific impairments and needs, and thus are more effective in promoting the relevant support from service systems. At the same time, cross-disability organizations of disabled people represent all disabled people in a community, so they may be more effective at the community level. Cross-disability

organizations are also needed at the national level to communicate with government regarding the rights of all people with disabilities. Both single and cross-disability organizations recognize that they are more effective when they collaborate on common issues.

DPOs find it necessary to focus on different groups of people with disabilities based on geographic or economic factors, such as urban and rural, or rich and poor. In rural areas there are very few DPO members. Even in urban areas, people with disabilities who are poor are not well represented. Children and women with disabilities, especially the poor, who may be exploited financially and sexually, usually do not have a voice in the organizations. DPOs are already aware of the need to be more inclusive. CBR programmes can help DPOs by enlarging their membership base at community level.

Involvement in DPOs goes from the basic--getting people into organizations--to the higher level of political power. DPOs can find ways to communicate with all people with disabilities. In rural areas, this may be possible through the Internet, or more likely, through radio. Personal outreach is also needed. Rural and poor groups in particular would benefit from education and vocational programmes that would increase their capacities to take leadership roles in CBR programmes.

The diversity of needs of persons with disabilities must be remembered, so that all different needs are answered. The disability organizations are willing to provide information and support, but they must be consulted. Certain groups of disabled persons are difficult to include, like those with multiple disabilities and those with intellectual disabilities, so extra efforts are needed to include them. For people with severe disabilities, like severe intellectual impairment, the social dimension is very important. Individuals have the right to live in the community and not in an institution. Communities can provide important support to parents of children with severe impairments, even if nothing specific can be done for the children's impairments. CBR could assume an active role in including persons with multiple or severe disabilities.

There may be difficulties between organizations of disabled people and those representing the parents, like those for persons with intellectual impairments. It is important to remember the differences between DPOs and NGOs. Good relations between the two can strengthen CBR programmes.

DPOs have shown that they can manage CBR programmes themselves, but they could also be willing to work with a variety of groups who are interested in CBR, such as non-disabled people who develop programmes. DPOs must work with many people who provide referral services to ensure that these services meet the needs of people with disabilities.

People with Disabilities Form Community Level Organizations

Organizing oneself is necessary in order to be able to speak to decision-makers. People with disabilities can organize in order to have influence at community and national levels. Resources and capacity building are needed in many parts of the world to enable people with disabilities to form or strengthen their associations. In order for DPOs to be effective at community level, they must have active members at this level. The organizations also need support in order to decentralise and to establish and strengthen themselves at the community level.

CBR could support the strengthening of DPOs so that they can begin to determine their own needs. To expand community-level organizations, existing groups could play a facilitating role,

fostering chapters or branches. Funding in the form of seed money is essential, as is capacity building. Building can go both ways--local groups building a national organization or national groups branching into local areas.

At the community level it is also important for people with disabilities to integrate into existing structures with non-disabled people. For example, women or young people with disabilities can integrate into local women's or youth groups.

Parents' organizations may also form through CBR programmes. Two groups of parents may come together at the community level--parents of children with disabilities, and parents who themselves have disabilities. Often these two groups work on separate issues, but they might strengthen their impact by coming together to promote mutual concerns. Parents' organizations can often play a key role in fundraising. This too could be strengthened through collaboration.

Some parents' organizations focus on the services needed for their disabled children, but do not address the overall issue of human rights. Hence, some DPOs are taking the responsibility to promote the rights and equal opportunities of children as well as adults. DPOs can work with other groups, but they may choose not to include others, e.g., parents or care givers, as members of their organizations.

People with Disabilities as CBR Workers

People with disabilities can be involved as workers and decision-makers in CBR activities. They are needed as advocates and sources of information for the rest of the community. They also become role models for inspiring and helping other disabled persons to become more active. It is important to identify and share good practice examples of the roles disabled people play.

Disabled persons may be blocked by prejudices, and by physical or sensorial barriers, from participating as CBR workers. However, disabled persons have to work with CBR, not just as community workers, but also as managers, accountants, etc. Support services, such as sign language interpretation, are needed and should be provided.

Knowledgeable people with disabilities are present in the communities, even though their knowledge may not be based on formal education. It is important that this potential is tapped. All disabled people belong to a minority group, which may result in discrimination that requires extra effort to overcome and to promote their active participation in community affairs. Disabled women face double disadvantage--related to gender and to disability. Efforts are needed to produce attitude change so women with disabilities are accepted as workers, trainers and managers in CBR programmes. Blind women in many countries are taking leading roles in advocacy groups, and forming their own organizations. Specific laws and affirmative action may be required for this. For example, a specific percentage of seats in committees or parliament may be reserved for women, and disabled women can be elected to some of those seats.

People with Disabilities in Decision-Making and Political Positions

People with disabilities must be present in decision-making bodies at all levels. Disabled women and men could be supported to take active roles in the political system, as voters first because they have the citizens' right to vote, and then as candidates so that they can bring forward the needs of disabled persons.

DPOs can advocate for formal representation in all levels, i.e., parliament, ministerial, councils, and national commissions. In order to get people with disabilities involved, it may be necessary to have affirmative action for a limited period of time. Perhaps quotas are needed for people with disabilities to participate in decision making at all levels. However, affirmative action will not work in all countries. International organizations, including donors and UN agencies, can mediate by strongly encouraging governments to involve DPOs in the decision-making for all funded projects.

There is a need to create opportunities for educational and career advancement that would enable people with disabilities to occupy higher managerial positions at all levels, from the community up to the national level.

4. Scaling up CBR Programmes

Government Services to All People

Government support is needed for scaling up CBR. Both DPOs and NGOs could lobby governments, and use media for this purpose, because without government funding and policy, scaling up will not take place. For this activity, strong DPOs are needed to monitor the commitment and support from the government.

There may be many other demands on the government, so ministries will have to be convinced. Governments want evidence-based practices, so CBR programmes must be ready to provide evidence. Examples of good practice from other countries, or other areas of the same country, can be provided.

The process for promoting CBR could start within existing frameworks. CBR can be established or strengthened as part of a funded national programme, e.g. PHC, education, or social welfare. It can also be linked with other existing programmes, e.g., a programme on poverty reduction. To lobby for such issues, disabled persons may need capacity building. Other organizations can help DPOs in doing this. For example, international support is needed for development. International donors and UN agencies can be actively involved, e.g., by proposing disability as a cross-cutting issue, and by ensuring that existing programs, such as Health for All and Education for All, provide services for people with disabilities.

Mobilise Community Resources

There cannot be just one model of CBR to be used in every country. Also, not every country can use the same methods to scale up a CBR programme. All communities, no matter how poor, have resources that they are willing to share. For example, time and labour are resources that are often provided by people in the community. However, to scale up from micro to macro projects, funds provided by governments and external agencies are also needed. Government involvement is important to mobilise the funds and the communities.

DPOs could help to make decisions about services at the community level. It is necessary to identify specialised services that can be mainstreamed at this level. Many services can be provided, but training of personnel is needed. The referral services that cannot be delivered at the community level also need strengthening, and better co-ordination.

Many NGOs and development organizations working in communities do not know anything about disability, so they need to be made aware of the issues. The success of existing CBR programmes helps to create awareness and to extend programmes to more communities and countries.

Specialised Services to Be Mainstreamed

One way in which governments could promote mainstreaming is to ensure that all new or expanded services are acceptable and accessible to people with disabilities. These services could include health, education, transport, and judiciary. In addition, all existing programmes in the community could be available to people with disabilities, e.g., job training, agriculture, business loans, etc. These programmes may need modifications so that they are accessible to disabled persons.

All professional curricula could address disability issues. For example, training curricula for teachers could address disability issues so that all teachers are equipped with the basic skills needed to work with children with disabilities. Governments could put a value on CBR by giving credit for professional development for courses on CBR.

DPOs can actively promote mainstreaming by supporting specific programmes, such as the inclusion of children with disabilities into local schools, and the inclusion of younger children in community day care programmes.

Strengthening Referral Services

Referral services are the weakest link in the delivery of services for people with disabilities. Not all of the needs can be answered through the CBR programme, so support from the referral system is essential. Thus, teachers, health care personnel, etc. need to be trained so that they can support and strengthen the CBR process. They can also be trained to transfer their skills to personnel at community level. Involving specialists and professionals in the initial phases of CBR and in activities like training can help to bridge gaps between CBR and the referral services.

Referral systems could work with people with disabilities so that services are improved to meet the needs of people with disabilities, who know their needs better than personnel in the systems. There could also be an interdisciplinary approach so that sectors work together.

A bridge is needed between communities and the specialists and institutions. A system may be needed where specialists from institutions are paid to go and visit the communities. At the same time, community level workers may lack information about the functioning of referral services, so organizing visits for community workers to familiarise them with various services may be useful. Bridges are also needed between private and public sectors, for example in employment.

There is also a need for an information system that is available at the community level as well as within the referral services. Within each country, a data bank could be put in place.

CBR and Poverty Reduction Programmes

A disability dimension could be included in poverty reduction strategies. This is appropriate because poverty and disability are interconnected. In every country, especially in those involved in poverty reduction programmes, there is a participatory process in which disabled people and CBR could get involved. This is the way to get CBR mainstreamed and to achieve scaling up. National programmes focused on development or poverty reduction could allocate 10% to 15% of the budget to address the measures needed for providing equal access for people with disabilities. This amount is based on the findings in different countries regarding the percentages of their populations that are disabled.

Reduction of poverty requires education al all levels from primary school to university, as well as job training programmes. All of these are of great interest in CBR programmes. Getting people with disabilities to work would change them from people who are economically dependant to people who contribute economically to society. People with disabilities need to identify their own needs and become part of overall poverty reduction strategies.

The indicators identified for the Millennium Development Goals include information about persons with disabilities. Representatives of CBR programmes and DPOs should collaborate to monitor the activities for reaching these goals.

Cost-Effectiveness of CBR

There is a need to demonstrate the effectiveness of CBR in order to convince governments and donors that it is important to fund CBR programmes. Research is needed to gather the necessary information. An important research technique relevant to CBR is Participating Action Research in which people are not passive research subjects, but actively involved in shaping, implementing, interpreting and disseminating research.

There are a number of considerations related to determining the cost-effectiveness of CBR. A variety of services in CBR programmes are voluntary, or are provided at low cost and not at market costs. There are a lot of voluntary contributions. There are human benefits that are difficult to cost, e.g., the well being of people within a community. Comparisons are needed, e.g., the cost of CBR services compared to the services for people in other health, educational, and social programmes. It could also be noted that methods for measuring cost-effectiveness are still underdeveloped. It is possible that some programmes may not be shown to be “cost-effective” because it is very difficult to measure their immediate and long-term results.

Some participants felt strongly that Disability Adjusted Life Years (DALYs) should not be used as a measuring tool because one cannot estimate the value of life, for example, of a blind person or a deaf person. This is an ethical and philosophical issue and not just an economic issue. It is most important to focus on the improvement of quality of life.

Recommendations

Following the discussions on the four topics, participants formed groups according to their affiliations. The following groups prepared recommendations for actions to be taken by their own groups:

- Disabled People’s Organizations (DPOs) Working Group: Recommendations to DPOs;

- Governmental Working Group: Recommendations to Governments;
- Non-Governmental Organizations (NGOs) Working Group: Recommendations to International and Local NGOs, Universities, and Professionals;
- United Nations Agencies Working Group: Recommendations to UN Agencies.

Recommendations to DPOs

Community Participation

1. Take a leading role in awareness-raising and advocating for the importance of CBR.
2. Become part of CBR programmes at all levels.
3. Raise awareness of the diversity of the different disability groups – of their specific needs and expectations.
4. Ensure that women and children are included in CBR programmes.
5. Ensure that CBR is included in all community activities.

Multisectoral Collaboration

1. Advocate for a national policy on disability.
   This policy should clarify the following:
   - Disability should be part of national goals within all sectors;
   - Each ministry should allocate part of its budget for specific CBR related activities;
   - There should be co-ordination bodies at all levels.
2. Encourage information exchange among different sectors and stakeholders.
3. Hold consultations among donors to ensure co-ordination of activities.
4. At global and national levels, encourage UN agencies and governments to implement the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

Scaling Up CBR

1. Develop mechanisms to make sure that disability issues are included in poverty reduction programmes, and that CBR is seen as an important strategy for poverty reduction.
2. Advocate that the needs of people with disabilities must be addressed along with the needs of all vulnerable groups in a society.
3. Advocate that disability issues are the responsibility primarily of government and should not be looked upon as issues to be addressed by only by NGOs.
4. Emphasise the importance of management and monitoring of CBR, and make sure that the disabled people are involved.

General: Promote the Following:

1. CBR should be viewed as a strategy;
2. CBR should be inclusive of all persons with disabilities;
3. CBR should be for all, including people without disabilities;
4. CBR should be used to address the essential need to build the capacity of DPOs;
5. CBR must be based on human rights instruments to address the needs of people with disabilities;
6. Define the roles of stakeholders: how the UN agencies and other international and multisectoral donors can address the specific needs of people with disabilities;
7. Advocate for the recognition of DPOs who have expertise in CBR;

8. Advocate for legislation to support CBR;
9. Re-define the term “rehabilitation”, which seems to be a only medical term.

Recommendations to Governments

1. Develop a national policy on disability in line with the UN Standard Rules.
2. Ensure an appropriate budget allocation by government and donors for CBR programmes.
3. Mainstream the national disability programmes with social and economic programmes, such as poverty reduction and the efforts to achieve the Millennium Development Goals (MDG).
4. Take a leading role in co-ordinating different stakeholders to promote a multi-sectoral approach to CBR.
5. Provide capacity building and funding for local DPOs and other CBR implementers.
6. Support the process to develop a UN Convention on the Rights of People with Disabilities.

Recommendations to International and Local NGOs, Universities, and Professionals

Community Participation and Ownership:

1. International non-governmental organizations (INGOs) to develop and disseminate advocacy materials;
2. Local NGOs to develop capacity of communities;
3. NGOs/Universities to work in partnership with communities for research on best practices and for dissemination of results to communities, policy makers and academic bodies;
4. INGOs/NGOs to involve community members in decision making policies.

Multi-Sector Collaboration:

1. NGOs/Universities to work with governments and UN agencies to analyse existing resource allocations across different sectors and lobby for increased allocation;
2. NGOs/INGOs to identify barriers to collaborations and identify mechanisms for more effective collaborations;
3. NGOs to collaborate with other NGOs involved in development activities;
4. NGOs/INGOs to collaborate with all government ministries, not only Social Welfare and Health.

Role of DPOs:

1. NGOs to work with DPOs to facilitate inclusion of people with disabilities from poor communities;
2. NGOs to facilitate the formation of community level DPOs;
3. INGOs to strengthen partnerships with international DPOs to work towards common goals, advocacy etc.;
4. NGOs/INGOs to involve DPOs in common projects.

Scaling Up of CBR:

1. Universities to collaborate with each other in Human Resource Development for different levels;
2. Universities/NGOs to work on evaluation and research on evidence-based practices, to help in decisions on scaling up;
3. NGOs/INGOs to emphasise better planning and management systems;
4. NGOs/INGOs to consider involvement in larger social movements.

General

1. Facilitate co-ordination among all stakeholders:
   - Have a clear vision of CBR;
   - Have a clear understanding of the roles of all stakeholders;
   - Develop a policy and clear strategies for co-ordination;
   - Promote co-ordinating bodies at different levels.
2. Promote participatory programme evaluation and research.

Recommendations to UN Agencies

Each Agency Should:

1. Be active in awareness raising, provision of information, and training on disability/CBR to national, technical line ministries;
2. Increase awareness, commitment, 'institutionalisation' of disability issues/CBR within the specific agency;
3. Monitor national government use of the UN Standard Rules related to the specific agency mandate, with DPO input;
4. Include disability in generic agency reports, databases, indices (e.g., Human Development Index);
5. Work to include disability/CBR in international initiatives, i.e., Health for All (HFA), Education for All (EFA), Global Employment Agenda (GEA), Youth Employment Network (YEN), and Poverty Reduction Strategy Paper (PRSP);
6. Work to influence donor priorities in favour of disability.

Agencies Together Should:

1. Promote CBR as a part of poverty reduction strategies and make the case for CBR itself as a poverty reduction strategy;
2. Work to make disability part of international, regional and national agendas, i.e., PRSP, MDG and New Partnership for Africa's Development (NEPAD);
3. Promote disability as a Human Rights issue, support 'multi-track' approach—UN Standard Rules, Human Rights instruments, and the proposed UN Convention on Disability;
4. Work to create thematic working groups on disability—international, regional, and country levels, involving DPOs;
5. Plan follow-up to this Consultation:
   - Finalise the Joint Position paper on CBR,
   - Organise a follow-up meeting,
   - Disseminate a copy of the report of this Consultation to each participant as well as to other international organizations and countries that are potential donors to community-based rehabilitation programmes.