

Request for Feedback **Deadline 15th March, 2004**

There are many occasions when the World Federation of Occupational Therapists is asked to make a position statement on relevant issues as part of its role as the key representative body of occupational therapists internationally.

The following document is Draft Position Paper on Community Based Rehabilitation (CBR) for the International Consultation on Reviewing CBR.

The Position Paper has been developed by the WFOT Project Team on CBR led by Frank Kronenberg. The team are very keen to hear what you have to say – they are waiting for your feedback.

HAVE YOUR SAY

Please forward any comments or suggestions to the WFOT Secretariat at wfot@multiline.com.au by March 15th, 2004

Many thanks

Marilyn Pattison
Honorary Secretary

Draft Position Paper on Community Based Rehabilitation for the International Consultation on Reviewing CBR

25-28 May 2003, Helsinki, Finland

**Organized by the World Health Organization (WHO)
in collaboration with other United Nations Agencies, NGOs and DPO's and hosted by
the Government of Finland.**

April 9th, 2003

**WFOT - CBR Project Team
February - May 2003
Principal Author
Frank Kronenberg**

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1. Introduction

The World Federation of Occupational Therapists (WFOT, www.wfot.org) is the key international representative for occupational therapists and occupational therapy around the world and the official international organisation for the promotion of occupational therapy. Founded in 1952, WFOT currently has 57 member associations.

The WFOT also established and operates the Occupational Therapy International Outreach Network (OTION), a grass roots initiative to promote outreach to areas of need by forming partnerships using the internet. The WFOT promotes occupational therapy as an art and science internationally. The Federation supports the development, use and practice of occupational therapy worldwide, demonstrating its relevance and contribution to society (mission). It is anticipated that a considerable number of occupational therapists world wide have been and are making important contributions to the development and implementation of CBR programs, demonstrating the synergy of occupational therapy and CBR. See Annex 1 for a list of occupational therapists with experience and expertise in the field of disability and development work. The WFOT is committed to the promotion of health and well-being from a human rights (occupational justice) perspective.

Background to this Paper

The development of this paper was initiated in response to and preparation for the International Consultation on Reviewing CBR from 25-28 May 2003, Helsinki, Finland. A WFOT-CBR Project Team (See Annex 2) is being established, aiming to identify and invite more occupational therapists from developing countries as well as people with disabilities (PWD) who have benefited from occupational therapy within CBR. Over 15 occupational therapists from eight different countries who have experience and expertise in CBR were identified and contributed their views to this paper (February-March, 2003). In a short period of time, a wealth of material worthy of more on-going discussion has been accumulated. More time and interaction is needed to digest all the different contributions and to articulate and reach consensus about the WFOT position on CBR.

The WFOT was formally invited to participate in this meeting by Dr E Pupulin (Coordinator, WHO Disability and Rehabilitation Team). This meeting is organized by the World Health Organization (WHO) in collaboration with other United Nations Agencies, NGOs and DPOs and hosted by the Government of Finland. The objective of this International Consultation is to contribute to the further development of the CBR concept and its implementation, by identifying the basic elements essential for effective CBR, through a review of current CBR practice and experience in a variety of settings (WHO Background paper, August 2002). The WHO meeting will include the INGOs involved in CBR, like Handicap International, Christoffel Blindenmission, Save the Children; all the major multi-sectoral agencies involved in CBR, including the UN Special Rapporteur on Disability, UN, ILO, UNESCO, UNICEF, UNDP, UNHCR, FAO. The World Bank will also participate as well as representatives from civil society and in particular International Disabled People Organizations (IDPOs) (WHO Background paper, August 2002). The WFOT Draft Position Paper on CBR will be put on the WHO International Consultation website and introduced to the working group sessions at the consultation. The WHO will also prepare a summary based on all submissions that they have received.

Status and purpose of this Paper

This text is presented as a draft paper that will be used for further discussion and development about the articulation of the WFOT position on CBR. The WFOT will consider the process and outcomes of the international consultation to contribute to its eventual position. The purpose of this draft paper is to:

- 1) Articulate the official position of the WFOT regarding the use, effectiveness and role of the CBR strategy internationally.
- 2) Describe the contribution currently being made by occupational therapists (including a list of identified 'experts' with experience in CBR, see Annex 1)
- 3) Note the challenges that are faced by occupational therapists and WFOT to achieve its proposed position.
- 4) List strategies to support CBR.

2. Proposed WFOT position regarding the CBR strategy

The WFOT supports all actions aimed at promoting and developing CBR and CBR principles as an important way to empower people with a disability in underserved and disadvantaged communities. Considering the service focus of occupational therapists—enabling people to choose, organize and perform those daily life activities that they find meaningful and useful in their environments, affording them with opportunities to gain greater control over their health and their destinies—occupational therapists are particularly able to facilitate the process of establishing CBR programme development at both government and community level. Occupational therapists are able to provide and pass on to community workers and disabled people relevant knowledge and skills to enable them to more actively participate in and take control of their lives and the lives of others within the community.

The WFOT supports the international community in the development of CBR as a strategy to develop civil society, to create healthy and accessible communities for all members, specifically those with disabilities and to extend equal opportunities for education, transportation, housing and employment for all members of the community.

The WFOT acknowledges that the concept of CBR is valid and possibly crucial for all countries, although it particularly speaks to developing countries, where services for people with disabilities are to be strengthened and expanded. Efforts must continue until all adults, youth and children with disabilities achieve equal rights and thereby have the same opportunities as other citizens in their societies.

3. Understanding of the issues/background - Current contributions of occupational therapists in CBR

WFOT acknowledges that different forms of rehabilitation exist, all being called 'CBR'. This paper is based on the definition of CBR as "a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services" (WHO/ILO/UNESCO, 1994). The major objective of CBR is to ensure that people with

disabilities are empowered to maximise their physical and mental abilities, have access to regular services and opportunities and become active, contributing members of their communities and their societies. Thus, CBR promotes the human rights of people with disabilities through changes within the community. CBR aims to include people who have disabilities from all types of impairments, including difficulty hearing, speaking, moving, learning or behaving. CBR also includes all age groups: children, youth, adults and older people.

The WFOT recognizes that in relation to specific and potential occupational therapy roles in CBR programmes the definition, principles, major objective and especially the emerging concepts related to **human rights** and **inclusive communities** of the CBR strategy fit well with the broad and also still emerging understanding of occupational therapy's domain of concern, that is; **occupation** (people's everyday functioning/social participation in daily life activities), its central approach of person-centred/**people-centred empowerment through enabling occupation**, and its foundation/ fundamental purpose of **occupational justice related** to opportunities and resources required for occupational participation sufficient to satisfy personal needs and full citizenship.

The WFOT acknowledges that the WHO has made a very important contribution through the development of the CBR concept and through facilitating the services. But WFOT also knows that there are still very many people with disabilities and disadvantaged communities who have no access to basic (re)habilitation services, who are not afforded with the rightful opportunities to choose, organize and perform those occupations that they themselves find useful and meaningful in their environment, i.e. self care, equal participation in schools, vocational training, work, recreation, citizenship roles, and other social and community activities. It is still estimated that only about 2% of the PWDs living in developing countries are currently receiving assistance. Even more significant is the evidence that many PWDs are dying prematurely due to their exclusion from the development process and lack of adequate services. Women and girls with disabilities and who are carers have often fewer opportunities than others and are more disadvantaged compared to disabled men.

CBR enables disabled people to organise themselves, in the daily context and habitat of people. It strengthens the capacity to analyse rights, needs and obstacles as well as the way to ensure development of personal potential, changing negative attitudes and breaking down barriers so that disabled people can become valuable members of their family, network, community, society. It promotes liaison with the different authorities involved to improve access and participation of all. This is why disabled people themselves need to be at the core of CBR. At the same time it is necessary that CBR principles and policies ratified at the national level are integrated throughout the different government sectors at the municipality, district, provincial as well as national level.

As a starting point for delimiting occupational therapy's contribution to CBR, the following **core ingredients of CBR** (IDDC, October 2002) will be reflected upon from an occupational therapy perspective:

- 1) Being community based;
- 2) Rehabilitation;
- 3) Cultural compatibility;
- 4) Utilization of local resources.

Being Community-Based means that the locus of control and action should be in the local community, with disabled people themselves, their families and community

members. Occupational therapy has in many places made the transition from institution to community based practice. Being present and interactive with the people in their most natural everyday contexts, where they live and experience, occupational therapists have demonstrated to be in an excellent position to gain first-hand knowledge and understanding about disabled people's everyday needs and interests, and support PWDs to make changes in the community so that the community as well as the individual benefits. A combined person- and community- centred process applies an enabling occupation approach which considers and integrates medical and socio-political knowledge and skills, which is also in tune with the WHO-ICF 2001. Occupational therapist facilitate people to be able to help themselves, individually and in the community.

The term **rehabilitation** has been heavily criticised by disabled people because of the negative connotations of being perceived as a medical term, and its lack of association with equalisation of opportunities and the removal of barriers in society. WHO and UN agencies have tried to rectify this situation by stressing that CBR does include the measures to bring about *social inclusion*. Increasing emphasis on human rights and community participation helps to clarify the essential elements and approaches for implementing the CBR strategy. Hence, it is clear that while CBR focuses on the rights of people with disabilities, it can also be a strategy that addresses the human rights of all citizens in the community. This links very well with *occupational justice*—a concept that Townsend and Wilcock (2003) introduced as a foundation and fundamental purpose of occupational therapy.

Cultural compatibility in CBR (IDDC, 2002) implies that CBR can respond flexibly and build on existing community traditions, structures, networks and activities such as the extended family, local committees, informal and non-formal education practices. It is an element that occupational therapists can be well prepared to work with, that is, if the people-centred approach is critically understood and applied to practice in the fullest meaning of the word. Jungersen (2002) raised critical awareness about this aspect using the term '*cultural safety*'. He recognized occupational therapists to work in many environments, where they must work in a culturally safe manner, moving beyond sensitivity and awareness to responsible action in a range of cultural contexts. He emphasized that practitioners must develop an understanding of their own attitudes, values and beliefs and how those beliefs influence practice, along with an ability to critically analyse 'taken for granted' assumptions of the world. Cultural safety involves a socio-political overview of practice; a critical awareness of the structures and processes that systematically marginalize people within society.

CBR programmes globally have developed ingenious ways of **utilising local resources** – people, material and finances (IDDC, 2002). Low cost aids and equipment can be produced from local material by local people and CBR programmes can empower PWDs and parents to take an active role in their communities and in CBR implementation. Ideally, practitioners that are trained in the art and science of occupational therapy, are well prepared to be resourceful and creative with whatever resources that are available.

To summarize, WFOT supports these key concepts of CBR:

1. The entire community (rather than simply individuals) being the beneficiary.
2. People with disabilities themselves are active participants in all aspects, including holding the decision-making power
3. Programmes are undertaken across sectors and/or disciplines.

Occupational therapy can contribute further to the support of CBR in skill and knowledge transfer, training workers to initiate and deliver services. Professionals are

often in positions as trainers and educators, where they can facilitate the development of new programmes by making their knowledge and skills accessible to community members and CBR programme workers. They can also ensure that they support community efforts by making themselves available and accessible on a referral basis. When they are in government service, they can advocate and promote the development of CBR programmes as an effective way to provide local-level services.

Occupational therapists can contribute in facilitating the CBR process – in enabling occupations and occupational justice, and in enabling individuals to participate in the process. Occupational therapists have knowledge and skills to support the development of good CBR practices and provide consultation to the CBR worker when s/he finds persons with more complex problems. The ability to facilitate others to become independent, makes the occupational therapist the ideal trainer for CBR workers to become leaders in their own community.

4. Challenges for occupational therapists & WFOT

Since CBR was presented about two decades ago, an evolution of concepts in CBR has occurred. Increasing emphasis on **human rights** and **community participation** helps to clarify the essential elements and approaches for implementing this strategy. The term 'rehabilitation' is perceived as a medical term and does not reflect the CBR concept. The occupational therapy key-concepts 'enabling occupation' or 'enablement' may be better suited to reflect CBR. The WFOT could challenge the current name 'CBR' to be changed to 'CBE'—Community Based Enablement.

CBR as a strategy not only focuses on the individual, family, community to assist them to provide low-cost and accessible rehabilitation but has to challenge society and duty bearers (state etc.) to ensure equal rights, to change negative attitudes towards disability and to break down barriers of all kind. It also has to work at different levels in order to be successful.

Occupational therapists need to develop their roles as **social change agents**, rather than just as professionals that make a difference at the level of people's individual lives. In order to become change agents, the education of occupational therapists must include a strong component on enablement, advocacy, and social reform.

Some of the challenges that occupational therapists and WFOT face include the following:

- **To functionalize concepts and strategies of CBR through occupation**

The WFOT recognizes that the definition, principles, major objective and especially the emerging concepts related to **human rights** and **inclusive communities** of the CBR strategy fit well with the broad and also still emerging understanding of occupational therapy's domain of concern, **occupation** (people's everyday functioning/social participation in daily life activities), its central approach of **people-centred empowerment through enabling occupation**, and its foundation/ fundamental purpose of **occupational justice** (building inclusive communities in which all people can realize their potential).

- **To explore gender and women's issues**

The WFOT has no stated policy on gender equality and women's empowerment, despite the large majority of occupational therapists worldwide being women. In line with CBR, WFOT may develop and promote a policy on gender equality and women's empowerment.

➤ **To explore the “political” aspect of promoting human rights within the framework of WFOT**

CBR is based on a *biopsychosocial* view of health and disability—a synthesis of the medical and social model (WHO-ICF, 2001). This view philosophically links very well with occupational therapy, but it can be argued, that the type of **knowledge, skills and experience** that the '**social**' perspective requires (ex. understanding of human rights, ability to analyse power inequities and imbalances, political lobbying, etc.) are generally **not well developed** by occupational therapists. Yet, these competencies are essential in leadership roles. Political skills (i.e. an ability to analyse power inequities and imbalances) are skills that few occupational therapists acknowledge. As social change agents whose aim is to improve the conditions necessary for optimal occupational performance of marginalized individuals and communities, occupational therapists must reflect on the political nature of their work with the people with whom they work in CBR.

➤ **To explore ways that occupational therapy can facilitate empowerment and community centeredness as well as the individual's needs to be able to get into the system**

Occupational therapists as facilitators can challenge invisibility, discrimination and poverty as major causes of the problems encountered by disabled people apart of facilitating people to develop their full potential and enable people to take part in different spheres and activities of society. In a lot of countries in the third world difficulties with prevention and rehabilitation have a lot to do with general issues of development, like economical issues (poverty), no infrastructure, no education, no democratic structures.

CBR not only produces improvements in a persons' functioning, but this is an important starting point for many disabled people to be able to access wider rights. In some countries (like Tunisia) people with disabilities have rights, but they are hindered by their social-economical cultural context in which they are not able to participate. Poverty, lack of infrastructure, and lack of facilities exclude them, more than their rights by law. Occupational therapists need to address how to facilitate empowerment, community development and community /people centeredness.

➤ **To facilitate ownership and good governance in CBR programmes**

Ownership of programmes is one of the greatest challenges. To be sustainable, a CBR program must be linked to some other greater organization, government or otherwise. Occupational therapists can facilitate the CBR group through the selection process to find such an organization in accordance with basic principles of good governance, social inclusiveness and equity. Poor governance and corruption are the main obstacles to sustainable CBR programs as noted in the 2000 UN report on poverty. Corruption is the first cause of poverty and ill-health. Occupational therapists should stress the importance of going beyond the immediate health needs addressed with CBR and consider from the inception of a programme what could be done in order to establish good governance.

➤ **To promote CBR, social change and leadership issues as an integral part of the education of occupational therapists**

The introduction of CBR concepts in the occupational therapy education programme is a good start to understanding the background and requirements of CBR, enablement, advocacy, and social reform. Providing community based programme and opportunities for students—urban and rural—reinforces a student's knowledge and

perceptions. CBR issues and occupational therapy should be studied, explored and developed, particularly at the Masters and Doctoral level. Postgraduate education is imperative to develop these 'leading ways' to supplement the undergraduate programme.

➤ **To facilitate research and the gathering of evidence**

It is assumed that participation, a fundamental aspect of CBR, will lead to sustainability of programmes, to equity and to empowerment, however no evidence of a causal relationship between participation and empowerment has been found. Since participation as a process (rather than a product) can not be measured, quantified, or replicated, its evaluation and measurement must be accomplished through qualitative research methods rather than the traditional collection of quantitative data. Research focused on process as well as outcomes in CBR must be supported.

5. Strategies to support continued development and sustainability of CBR

It has been observed, that implementation of CBR in different countries have varied a great deal, but some common factors have been identified that affect the sustainability of CBR programs. These include: 1) Recognition of the need for a CBR programme based on a human rights approach; 2) Willingness of the community to respond to the needs; 3) Availability of resources and support from outside the community; 4) Multi-sectoral collaboration, including collaboration with DPO's and NGO's; 5) Presence of community workers; 6) Integration of CBR within government with allocation of adequate resources.

Ad. 1: The Recognition of need for a CBR programme based on a human rights approach

Quite recently, Townsend and Wilcock (2003) introduced the concept occupational justice, advocating it to be promoted as the foundation and fundamental purpose of occupational therapy. Both this concept and occupational therapy's people-centred approach appear to link very well with the human rights factor that disabled and disadvantaged people themselves, and their families, ought to be enabled to define their needs, methods and paths to self-empowerment and self-integration. This seems to be the core principle and strength of the CBR strategy.

Ad. 2: The willingness of the community to respond to the needs

Collaborative and participative methods should be utilized to facilitate community based programmes. Occupational therapists can develop their understanding of and skills in Participatory Action Research (PAR). PAR is a form of collaborative research particularly concerned with power inequities of marginalized communities (Cockburn & Trentham, 2002). In order to further a facilitating role in CBR, basic skills about PAR or other similar research approaches are essential as facilitators of CBR need to start from the situation and context of disabled people themselves, in order to understand the dynamics and local resources to a. challenge various barriers and b. promote individual potential of disabled people. Occupational therapists can integrate these approach into CBR, and work together with clients and communities to address issues of access, inclusion, equity and collaboration in practice and research.

Ad. 3: The availability of resources and support from outside the community

Regarding this factor—the availability of resources and support—occupational therapists can enable disabled people in the communities with whom they work to advocate and lobby for the resources and necessary support based from a human

rights perspective (raising awareness and self-empowerment training), and help demonstrate that enabling people with disabilities to become active participants in the social, economic, cultural and political life of the community will contribute to improve the health of the whole community and the society at large. (WHO World Health Report, 2002)

Interesting examples can be provided by SARPV in Bangladesh where disabled people and families changed their roles from being excluded to becoming village mediators (water, sewerage, road connections lobbying etc). Or in Nepal where disabled young people formed groups (facilitated by Save the Children UK) made a movie 'inside outside' showing how they changed their role in the village simply by learning how to make a script, movie and how to distribute their experiences in popular ways. The role of facilitator here is to trigger the turn-over of roles.

Ad. 4: Multi-sectoral collaboration, including collaboration with DPO's and NGO's

Various actors and stakeholders working with people in marginalized contexts are under constant pressure and need to establish and maintain roles and relationships through on-going negotiation. This necessity of multi-sectoral collaboration in CBR, most explicitly requires occupational therapists and all actors involved to be (come) very aware of the political nature of CBR and their roles, which naturally implies the need to acquire basic knowledge of politics and political skills, in the broad and narrow meaning of the terms.

Ad. 5: The presence of community workers

Maintaining the commitment and motivation of the CBR worker—who most often seems to be a volunteer—has been observed to be one of the major challenges of community leaders and CBR programme managers. Here occupational therapists who initiate CBR programs ought to strive to enable people with disabilities and their family members to become CBR workers. The way that projects get started is through the interest and good-will of the person involved—and this may start out as a 'volunteer' situation.

Ad. 6: The integration of CBR within government with allocation of adequate resources

Skills and knowledge in writing the documents and project propositions to acquire funding are fundamental for the promotion and development of CBR. However, ultimately development takes place through on-going networking and lobbying activities. Organizational bodies in partnership with IDPOs must work closely with governmental sectors to ensure that their CBR programmes become integrated in governmental services with appropriate funding.

6. Conclusion

The WFOT recognizes that there are still very many people with disabilities and other disadvantaged populations who are marginalized and whose health and well-being are at great risk. It embraces the principle of building inclusive communities in which all people—including people with disabilities—can realize their potential (occupational justice) and is committed to promote and support the further development and implementation of CBR (and PHC) strategies to approach this principle.

This draft position paper underscores the commitment of the WFOT to promote and support the development and dissemination of CBR programs and the human rights of people with disabilities.

The person-centred approach of occupational therapy practice offers a good point of departure to facilitate the participation of people with disabilities in the

planning and implementation of CBR programs. However, the WFOT acknowledges the need to further operationalize and research the concept of the 'client' as an entire community (rather than simply individuals) being the beneficiary of the program. WFOT also recognizes the need to develop awareness of the political nature of the CBR (and PHC) strategy, and explicate its implications for the knowledge and skills that the different actors/stakeholders in CBR programs need in order to become more effective.

The WFOT will consider to adopt CBR as a policy and strategy to increase the number and improve the initiating and supporting roles of occupational therapists in CBR programs.

In her WFOT 2002 key-note speech "Action for Health in a New Millennium", Lisbet Palme called for society and the profession of occupational therapy to embrace a paradigm of including all its citizens in society. By supporting, promoting and increasing the engagement of occupational therapists in Community Based Rehabilitation (CBR) and Primary Health Care (PHC), the WFOT can answer and act on Palme's call.

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Annex 1

Identified experts working in CBR

- Debbie Kramer-Roy : debbiekramerroy@aku.edu
Senior Instructor, The Aga Khan University, Institute for Educational Development, Pakistan
- Hetty Fransen : h.fransen@gnet.tn
Working in Tunisia since 1994, as clinician, trainer, and lecturer with different NGO's, locally and internationally.
- Marlies van der Kroft : m.vanderkroft@scfuk.org.uk
(Disability Adviser Save the Children UK) Cooperates for SC-UK with WFOT in a WHO and ICH early detection manual en field-testing (Institute of Children Health University of London).
- Alaa Sebeh (SC-UK regional disability adviser for the region Middle-East and Northern Africa plays a key-role in this.
- Karin Murk : karin.murk@wxs.nl
Worked in Pakistan in a CBR project (took over when Marlies van der Kroft left). Went back several times to conduct courses (mainly for CBR workers) in the field of Early Intervention in relation with CBR.
- Laura Krefting : ldkrefting@yahoo.com
Development of CBR in Pakistan, Bangladesh, India
- Hanneke van Bruggen: j.e.van.bruggen@sz.hva.nl
 - Director of ENOTHE (European Network of Occupational Therapy Higher Education)
- David Werner : healthwrights@igc.org
Educator, author, health worker, person with a disability.
- Sabriye Tenberken : BrailleWB@gmx.net
Founder, leader of the Project for the Blind in Lhasa/TAR, author, who is blind.
- Lena Haglund : lena.haglund@inr.liu.se
WFOT Council, PBL OT Program, Linköping University, Sweden.

Other names available upon request

Annex 2

WFOT-CBR Project Team

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|------------------------------------|--|
| 1. Marj Concha (South Africa) | : etel@icon.co.za |
| 2. Frank Kronenberg (Netherlands) | : tulipan.rubio@worldonline.nl |
| 3. Tanya Packer (Australia) | : TPacker@exchange.curtin.edu.au |
| 4. Marilyn Pattison (Australia) | : marilyn@mpot.com.au |
| 5. Sheila Purves (Hong Kong/China) | : spurves@rehabociety.org.hk |
| 6. Salvador Simo Algado (Spain) | : salvador.simo@uvic.es |
| 7. Kit Sinclair (Hong Kong/China) | : rksincl@polyu.edu.hk |
| 8. Rachel Thibault (Canada) | : rthibeau@uottawa.ca |
| 9. Robyn Twible (Australia) | : R.Twible@fhs.usyd.edu.au |