

The World Health Organization (WHO) disability and rehabilitation newsletter is produced three times a year and distributed via e-mail. Subscription/unsubscription requests should be sent to WHO's Disability and Rehabilitation Team (DAR) at the following e-mail address: [pedersenr@who.int](mailto:pedersenr@who.int)

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On May 3rd, the Convention on the Rights of Persons with Disabilities (CRPD) enters into force, since Ecuador became the twentieth signatory. WHO and other UN agencies have signed a Joint Statement of commitment to promote and protect the rights of persons with disabilities and to work towards their full inclusion in the work of the United Nations.

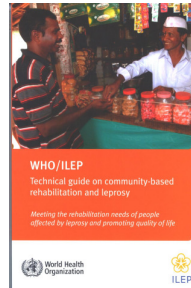
Fine words need to be matched by practical steps to operationalize the Convention. This newsletter reports on how WHO is achieving progress in different areas: supporting countries, addressing the needs of particular groups of disabled people and developing the World Report on Disability and Rehabilitation. Through these and other measures we hope to make a real difference to disabled people's lives:

*Knowing is not enough; we must apply.  
Willing is not enough; we must do.*

*-Goethe*

## CBR & leprosy

Leprosy is a curable disease: with early administration of multidrug therapy it is possible to halt progression and avert impairment. However, millions of people with leprosy live in isolation or in colonies, especially those who develop secondary visible deformities. People with leprosy-related disability usually depend on traditional leprosy centres which are mostly based in big cities and run by leprosy specialists. But such facilities are not accessible to all, particularly in the early stages of the disease.



In response to limited specialist provision, and following the Declaration of Alma-Ata (1978) declaring health to be a fundamental human right, the WHO introduced the community-based rehabilitation (CBR) strategy. In developing countries, CBR plays a major role in rehabilitation, as well as achieving social inclusion and poverty reduction, which are the primary problems for people with leprosy. CBR can deliver the goals of the UN Convention at the grassroots.

People with leprosy have traditionally been excluded from both mainstream rehabilitation and CBR, but changes of attitude mean that stigma is reducing. Because people are more likely to stay within their families and communities, involvement of family and community members is now seen as a key strategy to empower people affected by leprosy, encourage them to play an active role in their rehabilitation, and to further reduce stigma.

To support these changes, and to ensure that people with leprosy and their families benefit from CBR, WHO, in partnership with the International Federation of Anti-Leprosy Associations (ILEP), has developed a **Technical guide on community-based rehabilitation and leprosy**. This guide is a reorientation and familiarization tool for managers of leprosy projects and programmes, but is equally useful for CBR managers. It describes the principles, strategies and tasks of CBR as the appropriate response to the needs of individuals, families and communities affected by leprosy.

The guideline was launched during the pre-conference session of the 17th International Leprosy Congress which was held in Hyderabad from 30 January - 4 February 2008. For additional information, visit the ILEP website on <http://www.ilep.org.uk/>

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## CBR, prosthetics & orthotics next steps...

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Community based rehabilitation (CBR), has evolved considerably in the past 35 years into an effective strategy for rehabilitation and social inclusion of people with disabilities. But WHO recognizes that even in inclusive communities, many persons with disabilities require specialized rehabilitation services, for example those providing prostheses and orthoses (P&O). To strengthen the relationship between P&O services and CBR, WHO and the International Society for Prostheses and Orthoses (ISPO) produced a joint statement in 1999, revised in 2003, downloadable from:

[http://www.who.int/disabilities/technology/po\\_services\\_cbr.pdf](http://www.who.int/disabilities/technology/po_services_cbr.pdf). The statement calls for awareness of the role of CBR in P&O service delivery; CBR training for P&O personnel; CBR and primary health care personnel orientation on P&O. Since then, the World Health Assembly resolution on disability, the CRPD and the 12<sup>th</sup> World Congress of ISPO have all highlighted the importance of these actions.

In August 2007, a meeting between WHO and ISPO to develop an agenda of joint activities for the next four years concluded that little progress had been achieved on the relationship between CBR and P&O, and called for further work on the interconnections. ISPO and WHO are now planning a P&O and CBR consensus conference in 2009 - 2010 to promote these goals. We invite those active across these fields to submit examples of good practice to Steen Jensen, project manager, ISPO Copenhagen; [steen@ispo.ws](mailto:steen@ispo.ws).

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### Country focus: Ghana

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So how does this work on the ground? WHO, in collaboration with ISPO, undertook a high level mission to support the Ghana Health Services (GHS) to revive its national prosthetics and orthotics centre. The visit was a result of a direct request to WHO for assistance to develop physical rehabilitation services in Ghana by the Honourable Minister of Health H.E Major (Rtr) Courage Kwasihah.

In addition to WHO and GHS officials, the team consisted of Carson Harte, Executive Director of The Cambodia Trust, Sepp Heim, past President of ISPO and Harold Shangali, past President of ISPO and Dean, Tumani University, United Republic of Tanzania.

A detailed report has been submitted to Ministry of Health and GHS. It was evident from the mission and from a recent survey of rehabilitation in Ghana that considerable work is required to build capacity. Efforts are needed to strengthen both Institute-based and CBR services to ensure

people with disabilities can achieve a good quality of life. Key recommendations include:

- make better use of existing facilities in Accra;
- train existing workforce;
- train a new generation of professionals along WHO/ISPO guidelines;
- renovate and develop infrastructure;
- re-equip the workshops;
- strengthen satellite centers;
- mobilize resources and budget allocations.



WHO is grateful to CBM, USAID and ISPO for making this mission possible: it is hoped that USAID-Leahy War Victims Fund scholarships will be available to train

some of the existing personnel <http://www.who.int/disabilities/publications/technology/en/index.html> In this way, GHS can set up a model rehabilitation programme which will enhance the quality of life for thousands of people with disabilities.

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## World Report on Disability and Rehabilitation Regional Consultations

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The World Report is being developed at the request of the World Health Assembly (Resolution 58.23, 2005) and will be launched in 2009. It will provide a comprehensive, evidence-based global analysis of disability covering: data on disability; services to promote functioning and participation; rights and equality issues. The Report also identifies gaps in knowledge and provision and includes recommendations for action.

The provisional draft now goes out to four regional consultations. Authors and editors of the report will join with academics, service providers, policymakers, and disabled people's organizations. Participants have been selected for geographical coverage and complementary areas of expertise. These consultations will help identify gaps in the Report, provide additional sources of regional information, and shape the Report's conclusions. Participants will also assist with strategies for the launch of the Report at regional and country levels. This input is vital to ensure that the Report will be applicable to different regional and national contexts.

Regions represented: The Americas (San José, Costa Rica, 8-9 May); Africa & the Eastern Mediterranean (Harare, Zimbabwe, 28-29 May); Europe (Rome, Italy, 16-17 June); Southeast Asia & the Western Pacific (Manila, Philippines, 24-25 June).

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## Disability data counts!

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What is disability data, and why is it important? Understanding the prevalence of disability - the numbers of people with disabilities in the general population - is necessary so that policy-makers can understand need and plan service provision. The CRPD highlights the importance of data in Article 31: "States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention"

Traditionally, disability data was collected according to impairment categories - e.g. blind people, people with mobility problems etc. But this categorical approach is misleading, since it only counts those with severe problems, in specific diagnostic groups.

Since the International Classification of Functioning, Disability and Health (ICF), WHO's approach to disability data has changed. The ICF provides a broader picture of disability including the lived experience within physical and social environments. Data can be collected on the health component alone, recording a person's functional problems; or data can be collected on how this health component affects participation, in the light of environmental factors that help (e.g. assistive technology, accessible housing) or hinder (e.g. stigma, inaccessible workplaces).

Studies from India, South Africa and Ireland demonstrate that ICF based data collection results in a much higher prevalence of disability, with up to 10 times more individuals experiencing participation restrictions. A more accurate picture of the complete disability experience can help policy planners to create and fund services and opportunities that make a real difference to the lives of people with disabilities.

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## "New Paradigm" empowers people with disabilities in health care

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A research project entitled "New Paradigm of Medical Care for Persons with Disabilities", initiated in 2006, is working in six countries to study the feasibility and impact of a shift towards greater agency of people with disabilities requiring regular medical care, and better partnership with health professionals. Groups of people with specific impairments have been formed to share expertise and gain self care skills and information from health care professionals. Early findings indicate that these interactions lead to empowerment of people with disabilities and facilitate health care professionals' respect and recognition of their expertise when it comes to care. This action and

research initiative is jointly organized by DAR and the Italian Association Amici di Raoul Follereau (AIFO), in collaboration with Disabled Peoples' International (DPI).

In December 2007, a mid-initiative meeting was held in Rome for participating groups. Participants came from Colombia, Dominican Republic, El Salvador, Ethiopia, Italy and India. Different groups in the study include persons with spinal cord injuries, spina bifida, cerebral palsy, Down syndrome, epilepsy, leprosy related disabilities, diabetes, multiple disabilities, and other conditions. At the meeting, each project had an opportunity to share successes, and challenges.

Two main preliminary conclusions emerged. Firstly, participants concluded that the paradigm shift among persons with disabilities or chronic conditions requiring ongoing medical care is feasible and positive. With careful nurturing, the process can be empowering for individuals and families and contribute to better quality of life.

Secondly, they concluded that the paradigm shift among health care professionals is feasible and desirable. Although it can be challenging initially to involve them, it can lead to more job satisfaction and improved quality of work.



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## ANNOUNCEMENTS

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**1<sup>st</sup> CBR Asia-Pacific Congress**, 9-11 December 2008 at United Nations Conference Centre (UNCC), Bangkok, Thailand. Jointly organized by WHO, UNESCAP and the Government of Thailand and supported by ILO, UNESCO, JICA, CBM, HI, AIFO, NAD, ILEP and others. The Congress will be the first meeting of CBR practitioners from countries in Asia and the Pacific. Participants will share knowledge, experiences and developments in CBR related to the Biwako Millennium Framework (including Biwako+5), the Regional Decades of Persons with Disabilities and the CRPD. The Secretariat of the Congress will be housed at the Asia-Pacific Development Center on Disability (APCD). For further information, please contact Mr Chapal Khasnabis ([khasnabisc@who.int](mailto:khasnabisc@who.int)) or Mr Somchai Rungsilp ([somchai@apcdproject.org](mailto:somchai@apcdproject.org))

Rehabilitation International (RI) will host the 21<sup>st</sup> World Congress on **Disability Rights and Social Participation: Ensuring a Society for All** in Québec, Canada from 25 to 28 August 2008. The Congress will showcase the UN Convention and will bring together more than 1,500 global peers. For more information visit <http://www.riglobal.org>

