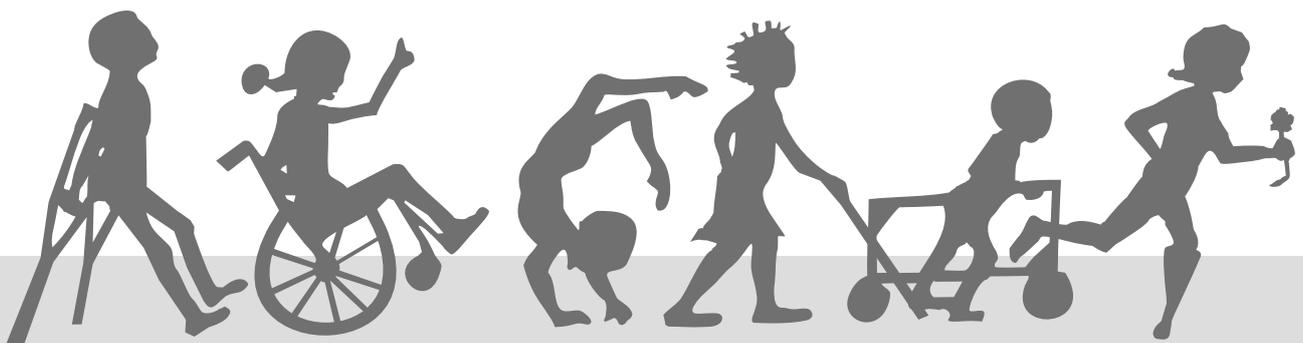


# Behinderung und internationale Entwicklung

## Disability and International Development



Von CBR zu Community Based Inclusive Development, Teil 1  
From CBR to Community Based Inclusive Development, Part 1





# Inhaltsverzeichnis Table of Contents

## Schwerpunkt/Focus

Von CBR zu Community Based Inclusive Development, Teil 1  
From CBR to Community Based Inclusive Development,  
Part 1

## Editorial .....3

The Origins of Community Based Rehabilitation  
*Einar Helander* .....4

Community Based Rehabilitation as a Strategy for Com-  
munity Based Inclusive Development  
*Maya Thomas*.....15

Inclusive Education for Children with Disabilities in the  
Highlands of Vietnam: Practical Experience of a Compre-  
hensive Approach  
*Pham Dung/Anneke Maarse* .....21

Community Based Rehabilitation: A Strategy for Promoting  
the Rights of Young People with Disabilities in Rural and  
Indigenous Communities in Oaxaca, Mexico  
*Flavia Anau* .....27

## Kurzmeldungen/Notes.....32

## Literatur/Reviews .....36

## Veranstaltungen/Events.....38

# Impressum/Masthead

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## Editorial

Liebe Leserinnen und Leser,

nach dem Weltbehindertenbericht der 2011 veröffentlicht wurde, ist Community Based Rehabilitation (CBR) eine relevante Strategie, um die UN-Konvention über die Rechte von Menschen mit Behinderung zu implementieren und das Thema Behinderung in der Entwicklungszusammenarbeit zu verankern. Das CBR-Konzept ist in den 1970er Jahren entwickelt worden, um Rehabilitationsdienste zu allen Menschen mit Behinderung in Entwicklungsländern – besonders in ländlichen und abgelegenen Gebieten – zu bringen. Seitdem hat es sich zu einer umfassenden Strategie entwickelt, die alle wichtigen Lebensbereiche umfasst. Dies spiegelt sich in den CBR-Guidelines wider, die 2010 veröffentlicht worden sind. Obwohl CBR als eine Strategie verstanden wird, die Entwicklungszusammenarbeit inklusiv zu gestalten, ist diese noch kaum von Mainstream-Entwicklungsorganisationen aufgenommen worden.

In dieser und der kommenden Ausgabe ist CBR unser Schwerpunktthema und soll genauer diskutiert werden. Wir beginnen mit der Entstehung dieses Ansatzes und beschreiben seine Entwicklung während der letzten Jahrzehnte. Verschiedene Artikel beschäftigen sich mit verschiedenen Komponenten der CBR-Guidelines und zeigen auf, wie Menschen mit Behinderung einbezogen werden können. *Einar Helander*, der das CBR-Konzept entwickelt hat, beschreibt nicht nur den Entstehungsprozess, sondern gibt auch einen Einblick in die historischen Hintergründe. *Maya Thomas* gibt einen Überblick über die Entwicklung von CBR bis zur Veröffentlichung der CBR-Guidelines 2010. Der Artikel von *Flavia Anau* demonstriert die Bedeutung des Konzepts besonders für ländliche Regionen. *Anneke Maarse* und *Pham Dung* zeigen für die CBR-Komponente Bildung auf, wie inklusive Bildung umgesetzt werden kann. In unserer nächsten Ausgabe werden weitere Komponenten der CBR-Guidelines beleuchtet werden.

In unserer letzten Ausgabe haben wir uns von langjährigen Mitgliedern der Redaktionsgruppe verabschiedet. Mit dieser Ausgabe freuen wir uns sehr, die folgenden Personen als neue Mitglieder begrüßen zu dürfen und danken ihnen für ihr Engagement: *Prof. Dr. Sabine Schäper* von der Katholischen Fachhochschule in Münster, *Isabella Bertmann* vom Max-Planck-Institut für Sozialrecht und Sozialpolitik; *Christine Bruker* von AGP Sozialforschung der Evangelischen Fachhochschule in Freiburg und *Jana Offergeld* von der Universität Münster.

Ihre Redaktionsgruppe

Dear Reader,

According to the World Disability Report published in 2011, Community Based Rehabilitation (CBR) is a relevant strategy to implement the UN Convention on the Rights of Persons with Disabilities and to include disability into development cooperation. The concept of CBR was developed in the nineteen-seventies, starting to bring rehabilitation services to all persons with disabilities in developing countries – especially to those in rural and remote areas. Since then it has been developed to a comprehensive strategy, which encompasses all important areas of life. This is reflected in the CBR Guidelines published in 2010. Although CBR is perceived to be a strategy to make development cooperation inclusive, this concept has rarely been taken up by mainstream development organisations and institutions.

In this and the next issue of our journal, the concept of CBR is our focus topic and shall be discussed in further detail. We start with its origins and describe its development during the last decades. Various articles reflect on different components of the CBR guidelines and show how persons with disabilities can be included: *Einar Helander*, who developed the CBR concept, does not only describe the process of drafting the approach, but also gives an insight into the historical background. *Maya Thomas* gives an overview of the further development of the concept until the publication of the CBR Guidelines. *Flavia Anau's* article demonstrates the relevance of the concept especially in rural areas. *Anneke Maarse* and *Pham Dung* provide an example for the CBR Education component and illustrate how Inclusive Education can be realised. Other components from the CBR Guidelines will be presented in our next issue.

In our last issue we said goodbye to several long lasting members of the editorial board. With this issue we are very glad to welcome the following persons as new members and would like to thank them for their commitment: *Prof. Dr. Sabine Schäper* from the University of Applied Sciences in Muenster; *Isabella Bertmann* from the Max Planck Institute for Social Law and Social Policy in Munich, *Christine Bruker* from AGP Social Research at the Freiburg Protestant University of Applied Sciences and *Jana Offergeld* from the University of Muenster.

Your editorial board



# The Origins of Community Based Rehabilitation

Einar Helander

This article reviews the creation and historical development of Community Based Rehabilitation (CBR). It is written by Einar Helander, a Swedish rehabilitation specialist, who in 1974 joined the Headquarters of the World Health Organisation, where he initiated and then during the next 30 years (until 2003) developed CBR.

## Introduction:

### The Historic Development of Services for Persons with Disabilities

Governments and charitable organisations have for centuries provided services for persons with disabilities in institutions (Helander 2011). The most visible effort had been the creation of vast orphanages, poor-houses and sanatoria. In the 1600s began the setting up of *specialised* services for persons with disabilities. One example is the Hotel des Invalides in Paris, specifically designed for disabled aged soldiers. Also in France, in 1784 Valentin Haüy invented relief characters for blind people; this system was further developed by Louis Braille in 1824, and with this started specialised schooling for blind children. Other, mostly boarding centres for children with disabilities had expanded, not only in the developed countries, but also in the developing ones, where by the 1970s there were thousands of these (Helander 1999).

In the 1970s victims of infectious diseases such as polio and leprosy were seen begging in the streets especially in large cities of the developing world. Immunisations of children was uncommon in these countries, this contributed to elevated incidence of visual and hearing impairments. Malnutrition was and still is a main contributor to elevated levels of disability and early death. More data about the causes of disability follow below.

Already in the 1960s the responsible Swedish authorities (my homeland) had issued official reports expressing the concerns about abuse, neglect and violence behind the walls of boarding institutions for children and adults with disabilities (Grunewald 1979). During 1968-74 I participated as Consultant to the Government's Board of Health and Welfare in the implementation of the goals of the Government to support independent living, full integration and participation, and an end to human rights violations. The Government involved organisations of persons with disabilities in all aspects and they received large organisational economic and political support.

International reports about institutional care at that time confirmed the hidden massive vio-

lence, neglect and criminal behaviour by the staff against the clients. An example was the Willowbrook State School in New York, which closed in 1988 (Rothman/Rothman 1984; Rivera 1972). It housed 6,000 persons with mental retardation; the clients were either naked or in rags and tags, many toilets could not be flushed, the odors were incredible, flies and other insects abounded. Buildings were un-repaired, roofs leaking, windows broken. There were almost no records of the clients; medical diagnoses were inaccurate, laboratory and physical evaluations absent. Proper food was not always available. There were countless reports of physical violence between staff and residents and among residents. An excessive number of deaths were ascribed to staff neglect. Willowbrook was "a symbol of public abuse against powerless citizens" (Rothman/Rothman 1984:36).

Another shocking experience came in 1990, when the Soviet Union broke up and the Central European countries under their power opened up. Most public attention was given to the orphanages in Romania. As Ceauşescu had during his 25-year reign forbidden all family planning, some 300,000 unwanted, healthy children had been abandoned by their mothers at birth and put in State orphanages, where they were subjected to severe abuse and neglect, many ending up with pronounced disabilities: unable to speak and with post-traumatic disorders (Helander 2011; Helander 2008). From 2002 to 2006 I went to Romania six times; we tried to rehabilitate these children, but had poor results. In all parts of the post-communist Europe there were similar, large orphanages.

During the years 1974-1989 when I worked for World Health Organisation (WHO), there emerged information that, for example, during my visits to Ghana, Mauretania, Indonesia, Pakistan, India, Iraq, Botswana and Guatemala children with visible, malformations were often killed at birth; in these decisions traditional midwives often were the instigators. Children with disabilities that appeared later in life, such as those with mental retardation, cerebral palsy



and autism rarely survived until adult age: The reasons of their deaths was mostly lack of medical care for respiratory infections, diarrhoea and malnutrition. In South Asia countries, girls with disabilities had lower survival rates than boys (Government of Nepal 1981; Gujarat Disability Household Survey 1997; Yacoub 1995). "Anyone handicapped in North Korea suffers terrible fates"<sup>1</sup> (Courtois et al 1999:560). They are exiled to remote mountainous regions or to islands in the Yellow Sea. Similar treatment applies to anyone out of the ordinary. People of small stature, for instance, were arrested and sent to camps and forced not only to live in isolation but also prevented from having children. Kim Jong Il has said that "the race of dwarves must disappear" and it seems they did<sup>2</sup> (Courtois et al 1999).

Boarding institutions, for example in Syria, Palestine, Egypt, India, Romania, Iran, Malaysia and Mauritius, were at my visits worse than horrible: naked children and adults sleeping in their own excrements, severe malnutrition, no education, and no health care. In combination the personnel left the clients without human contact and without any activities, children were not played with, no-one was talked with and just left sitting on a bed or laying on the floor. Consequently, in Romania two thirds of the children did not learn to talk and had severe post-traumatic stress disorder; it has been established that their health problems was related to brain atrophy (Helander 2011).

Another human rights problem was the virtual exclusion of children with disabilities from schooling, vocational training and employment. In many developing countries, adult persons with disabilities were not allowed to vote. In short: not only abuse and neglect were problems for the population of persons with disabilities, the general lack of justice, deprivation of participation and opportunities were added.

### **Past Rehabilitation Policies Focusing on Institutional and Specialised Care**

The WHO policies that existed in 1974 had been guided by groups of specialists, who had issued two Technical Reports, one in 1958 and the second in 1969. These reports contain policy recommendations and state-of-the-art technology descriptions and are distributed to all Ministries of Health of its Member States. The citations that follow (all from the 1969 Report) reflect the official view of the WHO.

The 1969 Report (WHO Technical Report Series 1969) states that rehabilitation is complex, involving several disciplines and different tech-

niques working together as a team in order to achieve the best end results for the handicapped persons. Rehabilitation should "establish schools for allied health and rehabilitation personnel...to promote rehabilitation faculties of medicine and create chairs of rehabilitation medicine" (WHO 1969:23). Medical rehabilitation centres should be set up – starting at the national level. These centres "should include facilities for both in-patients and out-patients. When in-patients have been rehabilitated sufficiently [...], they should become out-patients; and provided with transportation if they are unable to use public transport" (ibid:13). "The staff of a centre should consist of qualified specialists in rehabilitation medicine, nurses with additional training in rehabilitation, physiotherapists, occupational therapists, speech therapists and audiologists, clinical psychologists, prosthetists, orthotists, and social workers" (ibid:13). The rehabilitation team is recommended to also include: "vocational counselors, placement officers, special educators and recreational therapists" (ibid:15); and "the following consultants must be available: orthopaedic, neurological and plastic surgeons, internists, psychiatrists, orthodontists; etc." (ibid:16). The total (not including "etc.") comes to 20 different highly trained specialists. The Report states that the rehabilitation specialists "seem best qualified to deal with musculoskeletal dysfunctions. Other highly specialised fields need to have their own services" (ibid:17). "Since rehabilitation is expensive, its costs must be borne by governments with the help and cooperation of social security agencies where these exist" (ibid:10).

The final conclusion read, "WHO has an important part to play because the first stage of rehabilitation is purely medical, and further stages cannot be undertaken until the medical aspect has been dealt with. Nevertheless, any action taken to assist governments must encompass the whole field of rehabilitation, from medical care to the resettlement of the individual in the society; each victim of a disabling disease or accident needs to be treated, rehabilitated, and reinstated in society the most favourable medical, social, educational and vocational procedure" (ibid:22). The WHO report recommended that "rehabilitation procedures should be initiated in developing countries" (ibid:23), but they expected little or no action in these countries.

Most experts and organisations went on – well into the 1980s – claiming that the only hope for future rehabilitation services in the developing countries lay in the extension of the



pattern, described in the 1969 WHO Technical Report. Well knowing – or perhaps ignorant – that there were insurmountable problems associated with that system; they had in reality concluded that providing rehabilitation in the developing countries was not feasible in our times.

## The 1974 Report

At my arrival at WHO I was requested to issue by end of 1974 (WHO Document: Disability Prevention and Rehabilitation 1976) a Report to the WHO Executive Board on the global situation of disability and rehabilitation. At that time there were no scientific data about the global prevalence of the causes of disability. The problems with existing data were compounded by the lack of clear, international definitions of the term *disability*. I concluded that it would, however, be reasonable to provisionally assess that some ten percent of the global population had a disability (Killarney Expert Meeting 1969). A discussion of the prevalence and causes of disability follows later in this article.

I issued by end of 1974 a draft report with these conclusions:

- rehabilitation services are practically non-existent or grossly inadequate in developing countries;
- there is an apparent lack of national planning and coordination of services (medical, educational, vocational, and social, etc.) in most countries;
- medical rehabilitation services have usually concentrated on institutional care, with a low turnover of patients at a high unit cost;
- when advanced rehabilitation services and technology have been introduced in developing countries, the result has often been discouraging or a complete failure.

The current situation could only change if there were:

- emphasis on properly planned services, which meet the priority needs of the population;
- services are more easily accessible and give sufficient coverage as many tasks as possible should be performed at the community level utilising simply, but sufficiently trained local manpower and locally available materials;
- expensive institutions, complicated equipment and dependency on highly trained professionals are de-emphasised; when already in existence, such resources should be redirected to serve in the referral system that is necessary to provide supervision and continuous training;

- priority is given to technology directed towards quantitatively important problems that can be solved at favorable effectiveness/cost ratio, in response to the most pressing community needs.

The draft Report was during 1975 circulated at the WHO Headquarter for approval and then sent for review to the six WHO Regional Offices; there were no changes. In January 1976 the content and conclusions of my Report were adopted without any change by the Executive Board of WHO. What now lay ahead was to find a way to implement the changes.

## Field Analyses

### Meetings at the Central Level

During 1975-78 a series of developing country visits (Iraq, Syria, Lebanon, Jordan, Egypt, Indonesia, India, Congo, Botswana, South Korea, Philippines, Myanmar, Thailand, Vietnam) were made to evaluate the situation of persons with disabilities in developing countries<sup>2</sup> (Helander 1999). The responsibilities for services to persons with disabilities were mostly shared between several ministries, often with the Ministry of Social Affairs as main focus. With few exceptions, in developing countries health care and social staff had little knowledge of and even fewer skills related to disability, it was not part of their training programmes. Health care systems, such as those for maternal and child care seldom dealt with disabled children. The segregation of persons with disabilities was often part of the culture: no mainstream services, no health care, no education, no jobs, and no economic support. If existing at all, persons with disabilities had to attend segregated facilities. Persons with disabilities were mostly seen as unproductive, dependent on others for their daily functions and subsistence; many were severely neglected, lived in misery and died early.

When I was received by ministers and colleagues, they agreed that disability was a major health and social problem. They saw services as very costly, requiring large centres and expensive teams of personnel, unavailable in the country. The therapeutic results had not impressed them. Furthermore, their budgets had no allocations for such services in the present 5-year economic plans and none had been proposed for the following plan. If WHO could provide the funds, they would be happy to consider some project, but external funds had to be secured for a very long time.

In many countries there were small organisations of parents and of persons with disabilities. I usually met with them and we discussed



the problems. In some countries they had met with the Social Affairs Ministry and with a lot of pressure received some small funds to assist their organisations and members. Rarely did I see a national federation of these organisations; in some countries I convinced them to create one in order to give them more clout. These organisations rarely had rural members, although at that time some 85% of the population were rural.

### Learning from the People

After this mostly massive dose of discouragement I turned to the periphery: rural villages and marginal urban areas. There, I was accompanied by a national who knew the local people and could translate for me and explain the situation. At each place, I met with the community leaders to discuss the prospects of community involvement, of finding local employment, of ways to let persons with disabilities participate in informal job training. Then I would go to the school, follow some lessons and find out if any child with disabilities were there. The headmaster would then explain his views of the problems (Helander 1999). In some places I found empty schools; I was told that the teacher had a high absentee rate.

Then followed the home visits. During these preparatory years, I made several hundred interviews with and examinations of persons with disabilities and their family members. Parents told me how the disability started and what they thought had caused it. They related the problems and what they had done to cope. It was common to find their explanations of the causes of the disabilities influenced by common beliefs. Most parents had gone to a local healer for advice and afterwards, if available, to the health service. Those consulted usually failed to propose anything useful, and told the parents that their case was *hopeless*. Most parents were looking for a *cure* – some magic or medical procedure that would make the disability disappear. But most of them were willing to try training at home to improve the functional situation of the disabled family member.

### Detecting Indigenous, Spontaneous Rehabilitation

Among these hundreds of villages and urban slum areas visited, there were examples of adults with disabilities who had successfully trained themselves, and of children with disabilities whom family members had trained (Helander 1999). Examples were children with sequels of polio, who had been trained by parents to use home-made walking bars and

crutches and now could walk; blind persons who had learnt orientation and could walk around their villages using a tree branch; deaf children trained by an illiterate grandmother to use sign language and understand lip reading; children with learning difficulties who knew to eat and to dress and wash themselves. Virtually none of them had any access to rehabilitation professionals. They had no knowledge of anatomy, physiology, diagnosis, assessment techniques or anything else that in the industrialised countries is thought to be indispensable in rehabilitation. They had no commercially available equipment. Technical aids or appliances were produced at home or with the help of a local craftsman. Some had managed to go to school and later found their way unassisted to a job or to self-employment.

One important conclusion was that the spontaneous training was very similar in the countries that I visited in different parts of the world. The important question was: how could this indigenous technology be transferred to other people and to other countries?

The analysis based on the field studies concerned the elements needed to make such a Community Based programme sustainable.

Three components were considered:

- 1) Technical sustainability: the programme needed to have a technical manual that described in detail the tasks to be done. All who were to implement the programme needed such a manual translated to their local language. Local personnel had to be sufficiently trained to use this manual. A referral system should be developed, as more compacted interventions could not be made at the community level.
- 2) Cultural sustainability: the community members needed to get enough time to discuss and influence their rehabilitation programme. Other factors might influence the outcome of the CBR programme, such as those related to the local culture and its economic development.
- 3) Financial sustainability: can the resource inputs needed be mobilised and then remain in place? If there is outside funding (e.g. from an international or national donor) can the long-term dependency on such funds be avoided, so that eventually only national resources will cover regular service delivery costs?

Based on field experience and in accordance with the principles of WHO's flagship programme of Health for All (Declaration of Alma-Ata 1978) (of which rehabilitation was the fourth component) several more important pol-



icy decisions were taken. In the past, *conventional* rehabilitation had been concentrated around patients with musculoskeletal disorders. Although in the developing countries these disorders were very common cause of disability it was decided to include all other major group among them, examples are: persons with a) seeing, b) hearing, c) speech, d) moving, e) learning difficulties, and persons with f) epilepsy, g) mental disorder and h) leprosy. The reason was that it was inconceivable to create separate community programmes for each of these, and there were many examples of persons with combined disabilities. Some competence for these eight *sub-specialities* should be available at the first referral level; further specialisation, when needed, could be provided at higher levels. At the same time, WHO initiated the concept of the multi-purpose health worker along these same lines (Helander 1978). Directly connected to this change was the proposal to include rehabilitation aspects in all community development projects, not just in the health sector, but also with for instance, education, skills training, income generation, social services and human rights.

The next policy decision was to break with the conventional system. This had (in accordance with the 1969 WHO recommendations) usually started with the setting up of a *national centre*, in the belief that later on this centre would develop ramifications and decentralised services. In reality this had rarely been the case. National centres stayed national centres, and more often than not they turned into ivory towers. Now, the entry point was moved to the community.

In this spirit, the CBR system proposed to start all service development from below, by first encouraging the establishment of community services and, at a later stage, linking them to a referral system. The referral system should be created once the community needs of it were known, preferably after a period of implementation. In a system built from below, educational objectives for professional staff working at referral centres would be formulated in response to local requirements, while considering how existing resources could be restructured and decentralised. At its inception, a CBR system would be simple. Over time it should be upgraded from below, by improving community workers' competence through in-service training programmes. Parents or other family members who act as trainers of individuals with disabilities would develop their abilities through guidance and experience. Local schoolteachers could learn more about how to integrate chil-

dren with disabilities in the class, possibly with the assistance of a mobile resource teacher. Community leaders could start projects for integrated, informal ability training and help persons with disabilities to an income-generating activity. Communities would provide economic safety nets for those without any means for survival. Human rights must be better protected; and persons with disabilities and parents should obtain more say and better representation of their views.

The term *Community Based* contained yet another new policy. The decision to implement a local programme would be made in a decentralised system, where communities after proper information would decide if they thought that the programme had a priority interest to them. Their decision would not be influenced by pressure. There is a massive evidence that the technique of 'transplantation' of programmes using Western technology, service delivery systems and paid for by foreign donors with no or little involvement of the recipients often are unsustainable (Wignaraja 1996). Moreover, programmes integrating persons with disabilities in productive life has clear economic benefits (Helander 1979; Hammerman/Maikowski 1981). Communities that show interest in a CBR programme would have to agree to plan for, set up local management and to provide some local resources themselves, mainly a community worker (for example, when appropriate one for about 5,000 population).

The policy changes were significant and their implementation required many basic changes. CBR was a realistic, common sense system facilitating primary level rehabilitation, to be set up in poor countries. It was simple, and could be maintained using local resources available in all countries. CBR was the first WHO programme to describe itself as Community Based. From its entry point each country would develop their future systems based on needs assessments, the availability of local and national resources, the views of the stakeholders and adapting it to the local culture.

### **Development of the WHO Manual: Training in the Community for People with Disabilities**

In full agreement with the proposed major policy changes, WHO in 1979 provided a budget for the start of CBR implementation. Most of the funds from 1982 onwards came from SIDA, Sweden's development authority. Two consultants were recruited to assist with the preparation of the CBR technology: Ms Gunnel Nelson



from Sweden, an occupational therapy school principal who had worked several years in developing countries and, Mrs Padmani Mendis, a physiotherapy teacher from Sri Lanka with long international experience. They were to remain with the CBR programme for many years.

The draft Manual Training in the Community for People with Disabilities was completed by the end of August 1979. It had about 1,100 pages and 2,000 provisional drawings. There were (1) 20 training packages for the family, (2) four Guides for (a) the community worker (called local supervisor), (b) the school teacher, (c) the community leaders and (d) one with advice for how persons with disabilities could set up a local organisation to promote their own views and (3) an introductory chapter with managerial proposals, describing the principles and policies, and how to plan for, manage and evaluate the programme. All components had in-built evaluation. In October 1979, a meeting was held in Mexico City to discuss the testing of the manual with interested partners from nine countries.

Mrs Mendis and Ms Nelson went to the test countries (Pakistan, India, Sri Lanka, Botswana, Zimbabwe, Zambia, Nigeria, Mexico, and St Lucia) and assisted them to start their programmes. By the summer of 1980, the three of us made a first revision based on the field tests. The drawings were entirely remade. As test countries later on increased, we organised for the newcomers a three-week preparatory course in St Lucia in 1982. In 1983, we held a meeting in Colombo to discuss the results with a very large group; the second revision was produced during that year, it was extensive. This version was printed in a few hundred copies by WHO and distributed. Soon after came the first translations: Burmese, French, Malayalam, Singhalese, Somali, Tswana, and Urdu. The field-testing continued until 1986, it included revision of the evaluation programme, a review of the effects of the referral systems, countries that had requested assistance with their national planning. Several regional seminars were held to explain the principles and implementation of CBR. University Departments for Tropical Medicine, among them London, Liverpool and Uppsala started courses in CBR.

In 1987 started the final revision of the manual, built on the feedback we had got from hundreds of people who had taken part in the field testing. By that time, Ms Nelson had while at work for CBR passed away in a tragic traffic accident. She was succeeded in the manual revision by Dr. Ann Goerdt, Scientist at WHO. Some training packages were added.

As many of the users were semiliterate, the text was simplified. Specially designed programmes were set up using WHO's only! computer:

- 1) The words were checked against the Oxford list of the 2,000 most common English words. All words (except for such indispensable ones as disability, rehabilitation, etc.) not listed among those 2,000 were changed into Basic English.
- 2) All words used were listed in alphabetical order, indicating the frequency of each of them. To facilitate translations, words appearing only once, twice or thrice were replaced by synonyms, wherever possible. In this way we managed to arrange the text of 138,000 words limiting the number of different English words used to 1,300 in the training packages and to 1,500 in the guides.
- 3) A programme was produced for analysing sentences and marking out those, which were longer than 25 words. These sentences (with few exceptions) were then split into several simpler sentences, with a final average length per sentence of 11 words.

Besides the changes facilitated by the computer analysis, grammatical rewriting made all sentences very simple and straightforward. These became short, direct and have no double negatives. For clarity's sake, the text is somewhat repetitious. Each word carried only one meaning (e.g. the word *right* is used only as the opposite of *left*; the opposite of *wrong* is *correct*).

The technique for making drawings is based on a review of the existing literature on the use of illustrations in manuals and other publications for developing countries. It appeared that, apart from photos, line drawings alongside the text are the easiest to understand. The drawings have been field-tested and adapted accordingly. They have been made in such a way that local details such as dresses, hairstyles, houses, are easy to change to make them fit the actual environment. A professional artist redid 2,200 drawings.

At this point, I sent the various parts of the manual to 20 peer reviewers<sup>3</sup>. Their changes – they were rather few – were incorporated. The revision was finished in 1987 and the book (some 800 pages) delivered for printing. It took the Publishing Board of WHO and the printer two years until the manual came out in 1989. In spite of my repeated protests, the book was a luxury product, with many colours, glossy paper and very expensive. Few people in developing countries could by 1989 afford the US\$ 50 to buy it, so WHO had to give it away. Most



countries just acquired one manual, and then photocopied it. Many local translations were made, at present 50 partial or complete have been reported.

## The New CBR Policies

Information about new programmes in WHO need to be distributed internationally. At invitation I have written many articles (Helander 1978; Helander 1979; Helander 1980). A new WHO programme is also subject to policy documentation. One common way is to set up a WHO Expert Committee to review and explain proposed policy and programme changes and make recommendations.

The process came in 1981 with a one-week Expert Committee meeting held at the Geneva Headquarter (HQ) to issue a new Technical Report Series publication, which was finalised and approved during the meeting. It coincided with the United Nations International Year for Disabled Persons (IYDP, see below). Experts from all the six WHO Regions, staff and representatives from the United Nations, UNICEF, UNDP, ILO, UNESCO, the Council of the World Organisations interested in the Handicapped (a joint organisations of all major NGOs, including of persons with disabilities and parents), and the International Social Security Organisation participated; totally 23 experts.

The quotes below are from the official Report of that meeting (WHO Technical Report Series 1981). The discussions focused on the situation in the developing countries. These facts were recorded: "mortality among disabled children is much greater than among unimpaired children. Malnutrition, gastrointestinal and broncho-pulmonary infections are the main causes of these deaths. Morbidity is also higher. Disabled adults have lower incomes, and are more likely to suffer from poverty. Visibly disabled adult women are often abandoned by their husbands and deprived of their children. Disabled children have fewer opportunities to attend school. As adults they seldom get vocational training are often un-employed. Few of them marry and found a family. The presence of one child with visible and stigmatising disabilities in a family had negative consequences for the marriage of the brothers and sisters. Social segregation is widely spread because of deep-rooted fears and beliefs, originating from age-old cultural and religious convictions – for instance that the disabled are possessed or under divine punishment. The disabled are very often excluded from any position of leadership in their communities and in general excluded from planning

and decision-making in their societies. Their complete lack of representation in community affairs results in the neglect of their needs" (WHO 1981:11). "Community Based Rehabilitation involves measures taken at the community level to use and build on the resources of the community, including the impaired, disabled and handicapped persons themselves, their families and their community as a whole. Social integration is viewed as the active participation of disabled and handicapped persons in the mainstream of community life. In order to achieve this aim it is necessary to provide adequate rehabilitation for all the disabled and handicapped and to reduce to a minimum all handicapping conditions in all aspects of their environment" (WHO 1981:9-10)

The Committee recommended the following strategies and approaches:

- Prevention of disability through all types of measures within and without the health sector.
- Community Based Rehabilitation with the aim of total coverage of all populations.

In view of the high costs of institution-based rehabilitation the Committee recommended that it should be explained to the public that if a shift is made from institutional care to Community Based Rehabilitation, and if the relatives of persons with disabilities undertake to look after their family members with disabilities - equally good, if not better care - can be provided at much lower costs to society as a whole. There is much evidence to suggest that the training of persons with disabilities in self-care and provision of therapy at home by family members or other lay persons supervised by professionals give similar or better results than training directly by a professional in an institution. The Report was distributed to the Ministries of Health of all WHO Members States.

## Development of Managerial Tools

The development of the managerial tools was built on the experience from country visits. Already in 1975, there were requests from many developing countries for service and personnel planning. A number of early regional and country seminars were held with representation from the governments, professionals, service providers and representatives for organisations of persons with disabilities and of parents. It became evident that structured courses in management were needed, few of those who attended had ever made national plans, formulated objectives, generated alternative solutions to problems and calculated and compared their



cost-effectiveness, discussed how to analyse population needs and design curricula content based on such needs. It was common to copy such components from the developed countries, without any adaptations to the local realities.

Organised planning and monument courses were held for some 400 persons from over 100 countries, many of these in the 1990s until 2003. The following books and documents were produced and distributed both to the course participants from 90 countries and other interested:

- a) Training in the Community for People with Disabilities (Helander/Mendis/Nelson/Goerdert 1989)
- b) Prejudice and Dignity. An Introduction to Community Based Rehabilitation (Helander 1999).
- c) National Planning of Rehabilitation (Helander 1992)
- d) Quality and Cost Control of Rehabilitation Programmes. A Practical Guide on Cost-effectiveness and Efficiency Assessments (Helander 1993)
- e) A Service Delivery System for Community Based Rehabilitation. Guidelines for the Design of Training Programmes for the Personnel (Helander 1994)
- f) Sharing Opportunities. Disabled people's participation in mainstream programmes and services (Helander 1995).

In the 1990s and until 2003, these courses were held together with Mr. Ture Jönsson, a Swedish specialist in inclusive education with many years of international experience. He developed:

- g) Operations Monitoring and Assessment of Rehabilitation Programmes (OMAR); this included software for computerised evaluation of field programmes (Jönsson 1999).
- h) The first book about Inclusive Education (Jönsson 1996).

There have been many initiatives to continue technical and management training through national, regional and international meetings and conferences. The last was held in 2012 at Agra, India and was attended by 1,200 participants from 87 countries.

## The Environment of CBR During Its Development

The staff at WHO did not work in a vacuum. Some environmental factors were encouraging.

- 1) In 1976, based on a request from Libya, UN declared 1981 to be the International Year of Disabled Persons. This was followed by the UN Decade of Disabled Persons 1983-

92. During this period many countries implemented positive changes for persons with disabilities, and CBR programmes started in about 100 countries.

- 2) New organisations. In 1982 started Disabled People's International (DPI). It created a common contact point for all national organisations of persons with disabilities, and played an important role for the Convention on the Rights of Persons with Disabilities.
- 3) Human rights progress. My descriptions at the beginning of this article have made clear that the human rights situation for persons with disabilities was disastrous. Clearly this abusive system had to be changed. The introduction of CBR would help by replacing boarding care with day-care and family training programmes. Meanwhile, could more be done by official, international institutions and organisations that were concerned with human rights?

In 1978, I visited the office of the UN High Commissioner for Human Rights (HCHR) at Geneva. I described to a senior staff member the human rights problems of persons with disabilities, especially children. I wondered if HCHR could take a special initiative to deal with the "cruel, inhuman and degrading treatment" (this formulation is used in the 1948 UN Universal Declaration of Human Rights UDHR) of persons with disabilities.

I was told 1) that there was no reason for a special Convention, because their rights were the same as for everybody else, as formulated in the UDHR and the International Covenant on Civil and Political Rights (ICCPR)<sup>4</sup> and 2) the High Commission could not receive complaints about persons with disabilities, as there was no special Convention for them, and 3) to get such a Convention was not possible, because there was no political will among UN Member States. At his recommendation, I made a second visit a few weeks later to see the Deputy Commissioner and got the same answers.

The ICCPR is a legal treaty<sup>4</sup>. It had been adopted by UN in 1966, 20 years after the UDHR (which is not a treaty text and thus not legally binding). By 1978 - 12 years later, when I made my first visits to the Human Rights Commission ICCPR had been ratified only by 40 countries. One can understand the frustration of the Commission's staff. Moreover, many states then and later had made exceptions for parts of the text. Let me take an example. It took USA until 1992 to ratify ICCPR, but then its Government attached five reservations, five understandings,



four declarations, and one proviso. With so many exceptions, the ICCPR implementation has little, some say no, domestic effect.

The first step to arrive at a Convention was the presentation of *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities*, these were adopted by the UN General Assembly in 1993. Mr. Bengt Lindqvist, who is blind and later on became a Swedish Government Minister, was instrumental in getting these Rules written and approved. In 2000, leaders of five international disability NGOs issued a declaration, calling on all governments to support a special Convention. In 2001, the UN General Assembly, following a proposal by Mexico, established an Ad Hoc Committee to consider proposals for a comprehensive and integral Convention to promote and protect the rights and dignity of persons with disabilities. Disability rights organisations participated actively in the drafting process. The text of the Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the UN General Assembly on 13 December 2006 (34 years after my visit to the Human Rights Commission); it has now ratifications from 132 countries. The Optional Protocol to the Convention on the Rights of Persons with Disabilities is a very important side-treaty to the Convention which allows its parties to recognise the competence of the Committee on the Rights of Persons with Disabilities to consider complaints from individuals; without such ratification of the Protocol the Convention will be unable to do much about human rights abuses of persons with disabilities. Five years after its adoption a mere 77 countries have ratified that Protocol, representing only 16% of world total population.

- 4) New disability statistics. In 1996 the WHO Statistical Division published data about dis-

Cause	YLD million years
Unipolar depressive disease	55.3
Refractive errors	25.0
Hearing loss, adult age	23.2
Alcohol use disorders	18.4
Cataracts	17.4
Schizophrenia	14.8
Birth asphyxia and birth trauma	12.9
Bipolar disorder	12.9
Osteoarthritis	12.8
Iran deficiency anemia	12.6

Table 2: YLD, High-income countries

Cause	YLD million years
Unipolar depressive disorder	10.0
Hearing, loss adults age	4.2
Alcohol use disorder	3.9
Alzheimer and other dementias	3.7
Osteoarthritis	2.8
Refractive errors	2.7
COPD	2.4
Diabetes mellitus	2.3
Asthma	1.8
Drug disorders	1.7

ability. The term disability-adjusted life year (DALY) was introduced. It is a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death. The impact of disability is measured by: Years Lived with Disability (YLD). Projections are being made for year 2030. The latest YLD data (from 2004) appear in Table 1 and 2 (World Health Organisation 2008). There are differences: developing countries have more sensorial causes and more birth complications than the developed ones.

For all countries the new data show that mental disorders are among the most important causes of disability, totally one third of all disability is caused by these. It is a reminder to all involved in rehabilitation services that we have for a long time remained pre-occupied with persons with physical and sensorial disabilities, while under-serving those with mental ones. The service gap has been most visible in the developing countries. Many even leading persons in rehabilitation organisations, who I have recently asked, are either ignorant of these new data, or have not taken action to change their plans or activities to adjust them to the new realities. All organisations working in low and middle-income countries should start to strengthen programmes that provide services for persons with mental disorders (unipolar depressive disease, alcohol use disorder, schizophrenia, and bipolar disease).

### The Future of CBR

CBR was based on thorough study of the situation, the abilities and needs among persons with disabilities in the developing countries. The CBR is a strategy that defined a new entry point. Action to improve the quality of life of



persons with disabilities would no longer be based in highly specialised institutions away from the mainstream; it would be available next to those who needed them. Community mobilisation was identified as important. Changing the entry point also implied very thorough changes in the entire traditional system, including existing policies, supporting the empowerment of persons with disabilities and their organisations, providing better opportunities, and promoting their human rights. Using that entry point, each country should develop its own culturally adapted policies, plans, actions and services in a future system based on needs assessments, the availability of local and national resources, and the views of the stakeholders. After over 30 years the strategy still remains in the focus. In 1999 I made a summary of the priorities for the next decades (Helander 1999), I have now added a few points to the text below:

Proposed priorities for programmes concerning disabled people in the developing countries for the next decades

- a) making services available to all disabled people who need them, improving their access to general development and mainstream programmes (such as those for poverty alleviation), and creating more equitable opportunities for disabled people; programmes for persons with disabilities caused by mental disorders need to be emphasised;
- b) increasing resources for development of programmes for disabled people so that all essential needs of disabled people can be met. It is proposed that, as soon as possible, all development agencies make one per cent of their budgets available for this purpose. The co-ordination of the use of such resources should be improved;
- c) strengthening all efforts aimed at sensitising the public and making it more aware of the abilities of disabled people;
- d) developing an active local and national role for disabled people, their families and their organisations; empower them, so they will exercise their political rights;
- e) monitoring the human rights situation of disabled people, including equitable access to opportunities, protection against abuse and crime, and taking adequate corrective action when needed. It is especially urgent to organise international inspection of boarding institutions, and introduce alternatives to these: day-care centres and family training programmes, and provide economic and professional support to such families, when needed;

- f) improving collection and dissemination of information.

Some of this has taken place, but there is a long road ahead of us.

### Notes

- 1 My first information is from 1994, and originated from a World Food Programme professional, who told me that there were no more dwarfs in North Korea. Confirmation in Courtois 1999.
- 2 Official reports were submitted at the end of each visit and delivered to The Ministry of Health in each country.
- 3 A list of them appears in the Introduction to the Manual.
- 4 The basic HCHR treaties are two the ICCPR and ICESCR (the International Covenant on Economic, Social and Cultural Rights). The Convention is a separate set of treaties dealing with specific subjects: slavery, torture, children, women etc. The book *Lost Lives* contains a very detailed description of the global human rights situation, p.79-92.

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**Zusammenfassung:** Dieser Artikel fasst die Entstehung und die historische Entwicklung von Community Based Rehabilitation (CBR) zusammen. Er ist von Einar Helander geschrieben, einem schwedischen Rehabilitations-Spezialisten, der 1974 zur Weltgesundheitsorganisation kam, wo er CBR initiierte und während der nächsten 30 Jahre (bis 2003) weiter entwickelte.

**Résumé:** Cet article résume la création et le développement historique de Community Based Rehabilitation (CBR). Il est écrit par Einar Helander, un spécialiste en réhabilitation suédois, qui s'est joint au siège de l'Organisation mondiale de la santé (OMS) en 1974 où il a initié et développé CBR pendant les 30 prochaines années (jusqu'à 2003).

**Resumen:** Este artículo describe el desarrollo y la evolución histórica de la Rehabilitación Basada en la Comunidad (RBC). El concepto fue publicado por Einar Helander, un especialista en rehabilitación de Suecia, que fue nombrado en 1974 en la sede de la Organización Mundial de la Salud. Helander inició RBC y siguió desarrollándola en los próximos 30 años (hasta 2003).

**Author:** Einar Helander graduated as Medical Doctor (MD) in 1953 and took a PhD in biochemistry in 1957. He has been a Scientist at the U.S. National Institute of Health at Bethesda, Maryland. In 1963 he started the first Swedish University Department of Rehabilitation. 1968-74 he was the Senior Consultant to the Swedish Government's Board of Health and Welfare. In 1967, he started as part-time Consultant to the World Health Organisation's European Office. In 1974-89, he served as Chief Medical Officer for the Disability Prevention and Rehabilitation Programme at WHO's Headquarters in Geneva. He then held a senior post at the U.N. Development Programme, New York, from 1990 to 1998. Since then he has been a consultant to the World Bank and contributed to many NGOs and universities. For four years he was a visiting professor at The All-India Institute of Medical Science in New Delhi. He is now Professor of International Health and Social Policies at a Lisbon University, Portugal. Helander has authored some 2,500 pages of articles, reports and books on CBR and made working visits to 94 countries.

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# Community Based Rehabilitation as a Strategy for Community Based Inclusive Development

Maya Thomas

This paper traces the development of Community Based Rehabilitation (CBR) from its origins to its present understanding as a strategy for inclusive development according to the principles of the UN Convention on the Rights of Persons with Disabilities. The current relevance of CBR is discussed, in light of the support of international and regional frameworks and the recognition of the need to include disability into future versions of Millennium Development Goals beyond 2015.

## Introduction

Community Based Rehabilitation (CBR) was initiated in the early 80s, due to the failure of the conventional system of rehabilitation then prevalent in many developing countries, and the need for an alternative approach (Helander 1993). Based on the principles of primary health care, the focus was on coverage of rehabilitation services for persons with disability living in rural areas in developing countries, at costs that were affordable. The main strategy was transfer of skills to local people, including families (WHO 1989), thereby reducing the dependence on, and the need for, expensive institutions, equipment and professionals.

An analysis of over 50 evaluations of CBR (unpublished reports), conducted by the author in low and middle income countries over the last 25 years, reveal the changes in the way CBR was understood and practised then and now. In the eighties and nineties, most CBR projects were vertical in nature and very few were integrated into development programmes. The evaluations in those years looked at how many persons with disabilities were registered with the project, how many were covered and benefited from different services like medical rehabilitation (mobility, daily living skills, communication, home based rehabilitation); education (school enrolment, special education); social security schemes; some livelihoods activities; some social activities like participation in community, and acceptance by friends/neighbours. The focus of evaluation was clearly on services for persons with disabilities and their families; and on project staff and management. Recommendations from early evaluations were about improving staff capacity in rehabilitation skills; inclusion of persons with severe impairments and disabilities; improving participation of persons with disabilities/families in project activities and building their capacity; and improving community participation.

From the mid-nineties onwards there were

major changes in CBR, captured in the Joint Position Paper of WHO, ILO and UNESCO (2004) that defined CBR as "a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services" (unpaged).

The major objectives of CBR are defined in the same document:

- "To ensure that people with disabilities are able to maximise their physical and mental abilities, to access regular services and opportunities, and to become active contributors to the community and society at large;
- To activate communities to promote and protect the human rights of people with disabilities through changes within the community, for example, by removing barriers to participation" (unpaged).

Gradually, the scope of CBR activities broadened from medical and education activities to more focus on poverty and livelihoods; formation of self help groups; family associations; use of words like *inclusion*, *participation*, *barrier-free* in planning; focus on awareness raising, partnerships and networking; inclusion of marginalised groups like women with disabilities, persons with intellectual or multiple disabilities, psychosocial disabilities or those living with HIV; and inclusion of persons with disabilities in general development and poverty reduction programmes, going beyond disability-specific entitlements. Evaluation recommendations based on the author's unpublished work in recent years have to do with strengthening advocacy, strengthening linkages with government and mainstream development organisations, building capacity of self-help groups and family associations to become independent self advo-



cates, integrating community development principles and practice, and planning for sustainability.

CBR practice has changed from a medical orientated, often single sector (e.g. health or education), service delivery approach, to a comprehensive, multi-sectoral, rights-based one, focusing on creation of inclusive societies where persons with disabilities have access to all development benefits like everyone in their communities.

The growth of CBR in different regions of the world is evident from a WHO survey conducted in 2007: about 92 countries had CBR projects and programmes: 35 in Africa, 26 in Asia, 24 in Latin America and seven in Europe (Khasnabis/Heinicke-Motsch 2008). In Africa alone 280 CBR programmes are listed in 25 countries (Adeoye/Hartley 2008). CBR Congresses have been organised over the last decade in Africa, Asia-Pacific and Latin America; regional CBR networks have been established to sustain the CBR movement through training and information exchange, and there are plans to promote a global CBR network.

In the Asian region, specific reference to CBR is now found in the national level policies of Bhutan, India, Indonesia, Myanmar, Pakistan, Philippines, Sri Lanka, Thailand and Timor Leste, which is a significant change from the situation a decade ago. In Burkina Faso in Africa, CBR has been adopted as national strategy to support persons with disabilities.

Some key lessons learnt during CBR implementation include the importance for a nodal ministry at the government level to coordinate national coverage of CBR and to promote multi-sectoral collaboration; collaboration between government and civil society in promoting comprehensive CBR programmes; linking of community level rehabilitation activities to existing primary health care systems; awareness raising and advocacy across different stakeholder groups at the time of inception of CBR programmes; promotion of self help groups and associations of persons

with disabilities; effective supervision, guidance and training of CBR staff at the community level; and need to plan for coverage of CBR in a country in a phased manner.

Anecdotal evidence from the Asian region shows that there are some good practices in sustaining CBR. Self help groups and associations of persons with disabilities, who are the primary stakeholders for CBR, can contribute to sustainability. Linking these groups with other successful community based organisations, such as women's federations, can also be of help. Collaboration between local government, parents, and CBR staff has been reported to be successful in continuing some CBR activities; while including persons with disabilities into local level development councils can ensure that disability issues are included in development planning.

### Community Based Rehabilitation Guidelines

The CBR Guidelines of WHO (2010), based on the principles of the UN Convention on Rights of Persons with Disabilities (UNCRPD), and developed with active participation of DPOs, UN agencies, governments and civil society organisations, are an attempt to synthesise experiences from across the world to provide a unified understanding of the concept and principles of CBR. It is meant to address the concerns and gaps among different stakeholders across different regions in conceptual understanding, definitions and practice of CBR. By synthesising CBR experiences from different regions of the world, the CBR Guidelines help to illustrate ex-

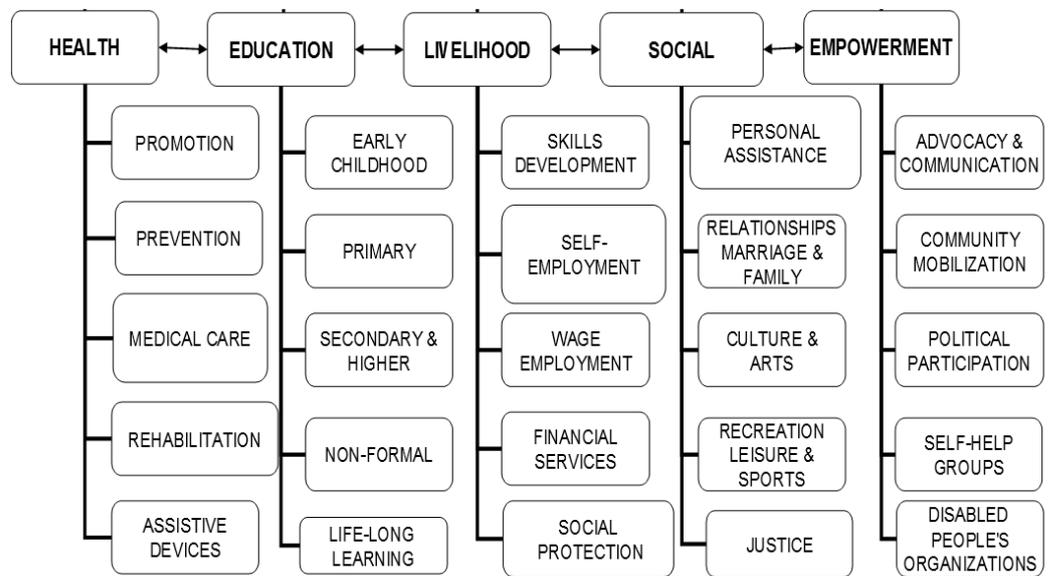


Figure 1: CBR MATRIX



isting and new concepts, and as such, they endorse and build on field level practice.

The Guidelines provide a structure for CBR planners and practitioners, based on which they can develop activities according to their local context, needs and resources. They do not advocate any particular *model*, as it has been understood for many years that there cannot be a single model of CBR for the world.

The CBR Matrix from the Guidelines (WHO et al. 2010:25) summarises the five main components of CBR and their subsidiary elements (see figure 1).

The Matrix can be used as a planning tool by CBR implementers, but it is clear in the Guidelines that the Matrix in totality is not expected to be implemented in every context. Programmes can choose the areas for implementation that are best suited to their local context, needs and resources; and explore partnerships with other organisations in areas where they lack expertise.

The CBR Guidelines can also be used as a guide to monitor and evaluate CBR programmes. The Guidelines suggest possible goals, desirable outcomes and activities for the different elements and components of the CBR Matrix. Planners and researchers can use these to develop appropriate indicators to monitor their CBR activities and to measure effectiveness and impact.

### CBR and the Convention on the Rights of People with Disabilities

The CBR Guidelines (WHO et al. 2010) state that: "CBR is a multi-sectoral, bottom-up strategy which can ensure that the Convention makes a difference at the community level. While the Convention provides the philosophy and policy, CBR is a practical strategy for implementation. CBR activities are designed to meet the basic needs of people with disabilities, reduce poverty, and enable access to health, edu-

CBR Guidelines	CRPD core articles
Introduction of CBR	3. General Principles
	4. General obligations
Main cross cutting themes: Women with Disabilities; Children with disabilities; principles of UNCRPD	3. General Principles 4. General obligations 6. Women with disabilities 7. Children with disabilities
Health	20. Personal mobility 25. Health 26. Habilitation and rehabilitation
Education	24. Education
Livelihood	27. Work and employment 28. Adequate standard of living and social protection
Social	12. Equal recognition before law 13. Access to justice 14. Liberty and security of person 15. Freedom from torture or cruel, inhuman or degrading treatment or punishment 16. Freedom from exploitation, violence and abuse 17. Protecting the integrity of the person 19. Living independently and being included in the community 23. Respect for home and family 30. Participation in cultural life, recreation, leisure and sport
Empowerment	4. General obligations 5. Equality and non-discrimination 8. Awareness raising 9. Accessibility 15. Freedom from torture or cruel, inhuman or degrading treatment or punishment 16. Freedom from exploitation, violence and abuse 17. Protecting the integrity of the person 21. Freedom of expression and opinion, and access to information 22. Respect for privacy 29. Participation in political and public life
Mental Health	25. Health
Emergencies and Disaster	11. Situations of risk and humanitarian emergencies

Figure 2

Source: IDDC. Community based Rehabilitation and the Convention on the Rights of Persons with Disabilities. Brussels, 2012 (Page 7)



cation, livelihood and social opportunities – all these activities fulfil the aims of the Convention” (WHO et al. 2010:26).

The Convention on the Rights of People with Disabilities (UNCRPD) contains reference to CBR in three articles, the relevant portions of which are given below:

Article 19: States Parties to the present Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community [...].

Article 26: States Parties shall organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

(b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

Article 25:

(c) Provide these health services as close as possible to people’s own communities, including in rural areas.

The strong linkages between the core articles of the CRPD and the CBR Guidelines are illustrated in a report published by the International Disability and Development Consortium IDDC (2012):

### **CBR and Community Based Inclusive Development**

The CBR Guidelines refer to *Community Based Inclusive Development*, a term that is increasingly being used today in connection with some programmes for persons with disability; and is sometimes taken to mean the same as CBR.

*Community Based Inclusive Development* is an aim or goal or an end result to be achieved – of making communities and society at large inclusive of all marginalised groups and their concerns, including persons with disability. The rationale is that no one should be excluded from development for any reason, be it gender, disability, ethnicity, refugee status, sexuality or any other issue. CBR is the tool or strategy to achieve the goal of *Community Based Inclusive Development* for persons with disability, just as other interest groups in the community (gender etc.), use their own strategies to make develop-

ment inclusive of their constituents.

Inclusive development also means that partnerships and alliances are necessary between different stakeholders, especially between CBR, disabled persons’ organisations (DPOs), families of persons with disabilities and governments (Thomas et al. 2010). Instead of dogmatic, *either/or* approaches and territorialism, all stakeholders need to work together to make programmes relevant and sustainable, to leverage other resources through wider networks, to capitalise on each other’s strengths, and to reach the goal of inclusive development with persons with disability as advocates. The development of the CBR Guidelines is an example of effective partnerships between multiple stakeholders – UN agencies, DPOs, governments, donor agencies and civil society including national and international non-governmental organisations.

### **How Relevant is CBR Today?**

The World Report on Disability (WHO/World Bank 2011) acknowledges that “CBR programmes have been effective in delivering services to very poor and underserved areas” (158). Evaluation studies from different parts of the world have documented the role of CBR in transforming lives of persons with disabilities. The CBR Guidelines (WHO et al. 2010:27), summarises some outcomes of CBR, based on published reviews. These include: increased independence, enhanced mobility, and greater communication skills for people with disabilities; increased income for people with disabilities and their families; increased self esteem and greater social inclusion.

Specific reference to CBR is found in national level policies of many countries in Asia and Africa. CBR practices are prevalent in many middle and low income countries today.

There are indications of a recognition of the importance of rights based approaches to disability issues: many governments in low and middle income countries have started mentioning the need for a paradigm shift from charity based approaches to a rights based approach in their policy documents. Countries with active civil society including DPOs that work in collaboration with governments have moved further ahead in this regard. These are positive developments, indicative of the will (in political and civil society sectors) to move towards a rights based approach. However, achievement at the ground level is uneven, with some available data showing that welfare and charity based perspectives towards persons with disabilities continue to prevail in some instances in



most countries (WHO 2012).

Despite the progress, much remains to be done. The World Report on Disability (WHO/World Bank 2011) has highlighted the fact that persons with disabilities lie behind in education and employment, have less access to health care, tend to be isolated from social, cultural and political participation, and families with a disabled member experience higher rates of poverty. Another recent study (WHO 2012) has shown that the majority of persons with disabilities continue to live in poverty, in remote areas that have limited coverage of health and rehabilitation services. Poverty and the resultant poor health care, lack of access to health care, lack of awareness, poor hygiene and sanitation, and communicable diseases, continue to be the largest contributors to the causation of impairment and disability in these countries.

In many countries, awareness on disability and CBR in government is low and needs to be improved. Since multiple ministries have programmes for persons with disabilities, the need for multi-sectoral coordination is recognised as important in effective implementation of policies. Some useful mechanisms for such coordination are in place in many countries, for example, a national co-ordination committee or a national CBR alliance, but it is also acknowledged that it continues to be a challenge in practice.

Of late, there has been some debate on the emerging challenges that CRR will need to consider and deal with. Yuenwah (2012) lists some that are relevant to the Asia-Pacific region: rapid urbanisation, increased incidence of non-communicable diseases, disasters and climate change, demographic transitions leading to increasing numbers of elderly persons, and economic challenges that can have an impact on poverty and food security.

In some countries, older persons constitute a disproportionately large group among populations of persons with disabilities. On the one hand, better health care access has led to increased longevity for many persons with disabilities; and on the other, longevity in persons without disabilities has led to higher incidence of age-related and other disabilities in the elderly population. It appears that people aged 80 years and above constitute one of the fast growing age groups worldwide. All the challenges faced by persons with disabilities in low and middle income countries – barriers in access to services; low availability and affordability of need-based services, especially in rural communities; and lesser numbers of trained personnel - will be challenges for ageing per-

sons with disabilities as well. The challenges are compounded by the fact that changes in traditional family structures have resulted in lower availability of care-givers and support systems in the community. In some low and middle income countries, population trends showing an increasingly ageing population has led to a situation where the younger people have to care for a disproportionately larger number of elderly persons in their families.

Addressing needs of elderly persons with disabilities, especially the varied health care and rehabilitation needs, can be cost-intensive. It is in this context that CBR programmes in low and middle income countries may be viewed as a possible cost-effective response to address the needs of older persons with disabilities in the community, since such programmes have many years of experience in working with families and communities in promoting inclusion and participation of children and younger adults with disabilities. In some countries, CBR programmes have already moved in this direction, for example, including elderly stroke survivors in home based rehabilitation activities, providing family education and counselling, and access to income generation.

## Conclusion

It is evident that CBR continues to be relevant and needed, especially in low and middle income countries, and that CBR can be an appropriate response and strategy to deal with some of the emerging needs and challenges in these countries. There are also some favourable conditions for continued CBR promotion worldwide. These include the support of international frameworks like CBR Guidelines, CRPD and regional frameworks like the third Asia-Pacific decade; the recognition of the need to include disability into future versions of Millennium Development Goals beyond 2015; the increasing interest and involvement of key stakeholders like governments and disabled persons' organisations in CBR; the emphasis on networking and sharing through national, regional and global CBR networks; and the current focus on evaluation and evidence-based practice to build up the body of knowledge on CBR.



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**Zusammenfassung:** Dieser Artikel zeichnet die Entwicklung der Community Based Rehabilitation (CBR) von seinen Ursprüngen bis zu seinem gegenwärtigen Verständnis als Strategie für inklusive Entwicklung entsprechend den Prinzipien der UN-Konvention über die Rechte von Menschen mit Behinderung nach. Die derzeitige Relevanz von CBR im Licht der Unterstützung durch internationale und regionale Rahmenbedingungen und die Anerkennung des Bedürfnisses Behinderung in zukünftige Versionen der Millennium Development Goals jenseits von 2015 einzuschließen werden diskutiert.

**Résumé:** Cet article retrace le développement de Community Based Rehabilitation (CBR) depuis ses origines jusque sa compréhension présente comme stratégie pour le développement inclusif selon les principes de la Convention de l'ONU relative aux droits des personnes handicapées. L'importance actuelle de CBR est discutée à la lumière du soutien des conditions générales internationales et régionales et de la reconnaissance du besoin d'inclure le handicap dans les versions futures des Objectifs du Millénaire pour le développement (OMD) au-delà de 2015.

**Resumen:** Este texto describe el desarrollo de la Rehabilitación Basada en la Comunidad (RBC) desde su comienzo hasta su actual entendimiento como estrategia de desarrollo inclusivo basado en los principios de la Convención de la ONU sobre los Derechos de las Personas con Discapacidad. Se discute la actualidad de la RBC dentro del contexto de marcos de acciones internacionales y regionales, así como la necesidad de incluir la discapacidad en las futuras versiones de los Objetivos de Desarrollo del Milenio a partir de 2015.

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# Inclusive Education for Children with Disabilities in the Highlands of Vietnam: Practical Experience of a Comprehensive Approach

Pham Dung/Anneke Maarse

WHO, ILO and UNESCO published the guidelines on Community Based Rehabilitation (CBR), in which Education is one of five domains. There are still lessons to learn on how to apply these guidelines in practice. This article presents the experience of a CBR programme supported in the Central Highlands of Vietnam. The focus of the article is the Early Intervention and Inclusive Education component of the programme. It is argued that a comprehensive approach, building a multi-faceted support network at different levels is essential to be able to respond to the diverse needs of children with a disability and their families.

## Introduction

Rules, attitudes and systems that are unresponsive to the needs of children with a disability often deny these children an opportunity for education. Excluding disabled children restricts their choices and makes it more likely that they will live their lives as adults in poverty, and has wider costs for society (Common Wealth Secretariat 2008/2012). The Dakar Framework for Action adopted a World Declaration on Education for All (EFA) in 2000, which established the goal to provide every girl and boy with primary school education by 2015. It also clearly identified Inclusive Education (IE) as a key strategy for the development of EFA. The fundamental principle of EFA is that all children should have the opportunity to learn. The fundamental principle of Inclusive Education is that all children should have the opportunity to learn together (Peters 2003). The role of CBR is to work with the education sector to help make education inclusive at all levels, and to facilitate access to education and lifelong learning for people with disabilities (World Health Organisation 2010).

With the development of the guidelines on Community Based Rehabilitation (CBR) (World Health Organisation 2010), the definition of Inclusive Education has also changed. Where CBR focuses on removing barriers in society, similarly Inclusive Education has moved its focus from changing the student to fit the system, to changing the system to fit the student (Peters 2003). Policy-makers have become interested in wider issues of social inclusion and how education might play a role in promoting social cohesion in societies that are increasingly diverse, socially and culturally (Armstrong et al. 2011).

## Vietnam, Disability and Inclusive Education

Vietnam is a developing country with a high rate of disabilities. The results of Census 1999 show a rate of children with disabilities of about 1.7% (Law on Child protection, Care and Education of Vietnam 2004) while the Vietnam Household Living Standard Survey 2006 estimates the rate of children from six to 17 year old with some kind of functional limitation (further called a child with a disability, a CWD) to be 3.8% (Ministry of Education and Training of Vietnam 2005). The current researches in the field of disability find that about 995,000 children (out of total 28 million children in Vietnam) are living with disabilities, equal to the rate of 3.4% (General Statistic Office 2000). A national study Situational Analysis of Education for Children with Disability conducted by Ministry of Education and Training (MoET) (Law on Child Protection, Care and Education of Vietnam 2004) in 2006 provides more specific statistical figures. Among almost one million CWD, 12% have a hearing impairment, 14% are visually impaired; 13% have speech difficulty and 19% of the CWD is living with a mobility difficulty. Children with a learning difficulty take the highest rate of 28%. (Law on Child Protection, Care and Education of Vietnam 2004). The research finds a wide range of causes of disability, as a part of which the burden of the long war and the limited quality of health care for pregnant women and children under five years are considered as the most important factors.

The Government of Vietnam is committed to ensure that all children regardless of their backgrounds are provided with education and favourable conditions to fully and relevantly participate in the educational system. In December 2007, Vietnam ratified the UN Convention on the Right of People with Disabilities (CRPD).



Most recently in 2010, a National Law on Disability was approved by National Assembly, which confirms the commitment to the implementation of the CRPD. This law affirms Inclusive Education as a part of the general education system in Vietnam.

Inclusive education was firstly introduced in Vietnam in 1986 by the International Non-Governmental Organisation (NGO) Radda Barnen. After almost 20 years, the situation of education for CWD in Vietnam is still meeting many challenges. Even though the Vietnamese education system is gradually moving toward Inclusive Education, there is still a large number of CWD who do not yet have access to the education system. To reach the targets of education for CWD the contribution of NGO is much needed. This paper aims at sharing the experiences of Medical Committee Netherlands Vietnam with implementing an Early Intervention and Inclusive Education programme as an integrated component of a comprehensive Community Based Rehabilitation (CBR) programme in Dak Lak province, located in the Central Highlands of Vietnam.

## MCNV and Its Support to Education for CWD in Highland Centre of Vietnam

The Medical Committee Netherlands Vietnam (MCNV) is a Dutch NGO that started to support Vietnam in 1968 through health care programmes. Support for persons with disability is integrated in all community health activities supported by MCNV. Besides MCNV is supporting a number of disability specific programmes. One of these programmes is implemented in Dak Lak Province, in the Central Highlands of Vietnam.

Dak Lak is a large, poor mountainous province of Highland Centre of Vietnam with a population of about 1.8 million people consisting of 44 different ethnic groups. Almost one third of the population of Dak Lak lives in remote areas where it is very difficult to access basic health and education services. Data of the local government of Dak Lak show that 11% of the total number of children has some kind of functional limitation. This is much higher than in other regions of Vietnam and is related to the impacts of war, for example due to the use of Agent Orange. In Dak Lak, CWD and their families face many challenges due to poverty, social stigma and lack of knowledge and skills to provide the necessary support to respond to the special needs of the child. Many of the CWD are not going to school.

Since 2000, MCNV is implementing a programme to support CWD in Dak Lak Province, in close collaboration with government partners. The programme is implemented in 54 communes out of 165 communes of Dak Province. The main goal of the programme is *to provide children with a disability with comprehensive support to develop their full potential, and to create the enabling conditions for their inclusion in the community*. The programme started as a Community Based Rehabilitation programme with an initial focus on physical rehabilitation. Over time, in line with identified needs, the programme has been paying more attention to education for CWD. It was observed that to be able to implement a successful inclusive education programme, it is important to start support as early as possible. This is why an Early Identification and Intervention component was added to the programme. The comprehensive objectives of the programme can be found in box 1.

### Box 1

#### The specific objectives of the programme are:

- 1) To detect CWD and provide them with adequate support as early as possible;
- 2) To provide CWD with proper health services as well access to suitable education with focus on inclusive education;
- 3) To improve incomes of poor CWD's families contributing to their quality of live;
- 4) To improve the capacities of organizations and institutions working in the field of support CWD such as health, education, social and mass media organisations<sup>1</sup>; and
- 5) To improve attitudes and perspectives on CWD in communities by raising awareness on the rights and potential of CWD.

The expected changes that MCNV and its partners try to achieve in education for CWD are identified at different levels:

- At child level: all CWD, including the most marginalised or excluded have access to learning and resources that meet their needs and respect their rights
- At school level: local schools include all children. The school are to be friendly, accessible, properly resourced and have a flexible curriculum. The teachers are well trained and supported and have a good links with families and community
- At community level: the community realises the potential of children with disability to learn and offers support and encouragement
- At educational system and institutional level: Early childhood, formal, non-formal and life-



long education initiatives fully include CWD and there is a good collaboration between health, education, social and other sectors.

## MCNVs Approach to Support Inclusive Education

As CWD have diverse needs the programme was designed in a comprehensive way to ensure effectiveness and sustainable impact of the programme. The approach is based on a twin track approach to inclusion, as also described by the Common Wealth Secretariat (Common Wealth Secretariat 2008) as the "best way to promote inclusion". The two tracks mentioned here are i) a focus on the child by early identification and support *and* ii) a focus on the system by making sure that conditions are in place for the child to develop to his or her full potential.

Figure 1 describes the model of needs based service delivery to CWD. Support for education for CWD is implemented alongside other components of support like medical rehabilitation, income generating activities (IGA), and empowerment for CWD and their families. The CWD and their family are at the centre of all kind of support.

*Medical intervention* is needed for most children having mobility difficulties. In the programme there is a high rate of children with Cerebral Palsy and children with a clubfoot.

Medical interventions can consist of operation, provision of assistive devices or rehabilitation exercises (mainly physical therapy). These interventions help children to participate more easily in the regular school activities. Further Village health workers and commune health staff play an important role in early detection of children with developmental delays and referring them to higher level for identification of disabilities.

Although *income generating activities (IGA)* do not directly relate to quality of education for CWD it still plays an important role. The parents of CWD often do not have time to take care of their child and/ or support their education process because they are working out of the house. With support from the programme families can have access to a loan and skills training to be able to start up a small home based business, such as pig or cow rising. This way families can improve their economic situation, and a caretaker can be around the house to support the CWD to develop and learn. Besides, an improved income enhances the nutrition status of the family, which positively influences the well-being and learning capacity of the child. The Dak Lak Woman's Union is the main partner for the IGA component of the programme.

*Empowerment* for CWD is a key strategy to create a supportive and barrier-free physical, social and policies environment for inclusion of

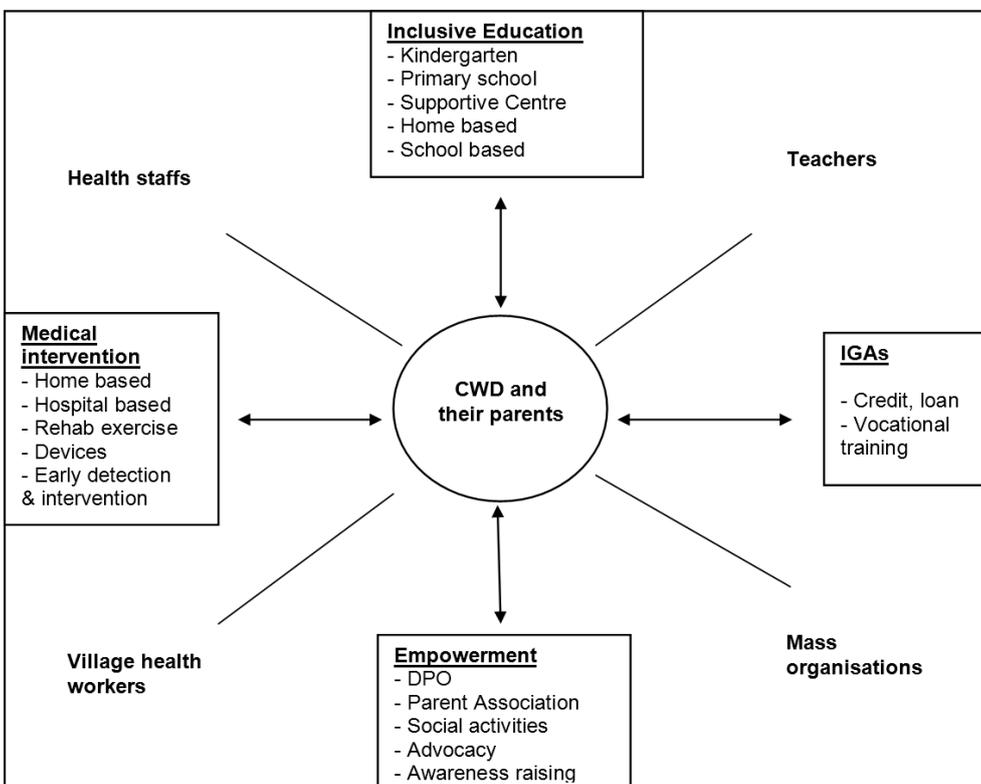


Figure 1: Components of support CWD

CWD. In Dak Lak, the programme has supported the establishment of Disabled People's Organisations and Parent Associations that are playing an important role in lobbying and advocating for better (educational) services for children and adults with a disability. Besides, the programme conducted several activities to raise community awareness, like inclusive sport and social events.

*Inclusive Education* is the main component of the programme to support CWD. The programme is organised from a Provincial Support Centre for education for CWD.

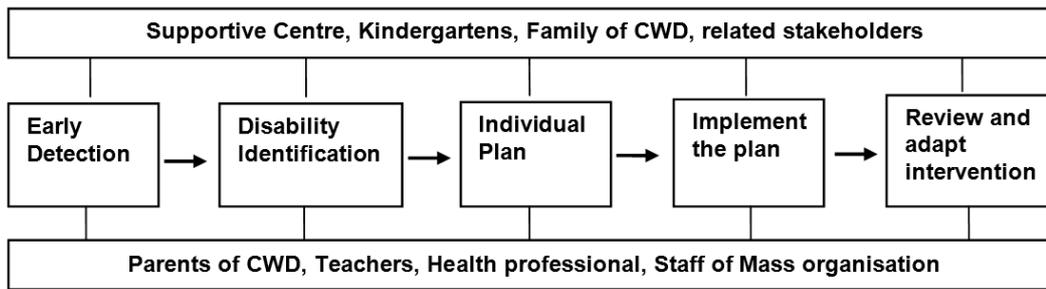


Figure 2: Road map of support C

This centre evolved from an existing special school for hearing impaired children and at present plays a key role in providing technical support for inclusive education teachers. The centre acts like a resource centre and is responsible for development of human resources for inclusive education at both pre-school and primary school level. The Support Centre also provides early intervention and special education services for children with major special education needs. Early intervention services are important to prepare CWD for inclusive education at regular kindergartens.

Figure 2 shows a road map for support for CWD within the Inclusive System of Education and Early Intervention in programme. Firstly, children with developmental delays are detected by health staffs, teachers, or parents. On the basis of a comprehensive assessment by rehabilitation and educational experts a diagnosis is made, and a comprehensive rehabilitation plan is designed. Children with special needs that enter the education system will have an Individual Educational Plan (IEP). Step 4 consists of implementing the rehabilitation and education plan, regular assessment and evaluation of progress is required to make sure to adapt the support plan when needed.

The strength of this approach is that the child-focused interventions as mentioned in figure 2 go hand in hand with other interventions that address the system around the child as mentioned in figure 1. With the system we mean the family, school and community, as well as policies and structures. This is possible because of the fact that the inclusive education activities are rooted in a comprehensive CBR programme.

## Results

The development of the comprehensive programme to support CWD in Dak Lak province has been an iterative, long term process where learning from practice has been a central driver. The education component of the programme has had a major impact on the access

to education for CWD in this province. By the end of 2012 the rate of CWD in project areas that is involved in the inclusive education programme was 80%. The rate of CWD from three to six

year old attending regular Kindergarten and receive Inclusive Education was about 65%. As for the CWD under three years old, 70% of them receive home-based education. Almost 70% of the kindergartens in the project area are implementing Inclusive Education (Education Department of Dak Lak province 2012).

### Box 2

Y An lives with his family in one of the poorer districts of Dak Lak province. He was admitted to the Support Centre for Inclusive Education of Dak Lak in 2010 when he was five years old. When An came to the Centre he was a very timid child, liked sitting at the door all day long, huddling up and watching other kids playing and running around, with no sign of speaking or smiling. Y An has one paralysed leg that seems to make him feel shy.

Y An comes from a farming family. During the entry interview his parents mention that Y An is not playing with other children in his neighbourhood; he is not going to school. While his parents are out during the day busy with farming, Y An is locked in the house.

As a part of the Inclusive Education program Y An got physical, educational, social and daily living skill therapy and he makes good development progress. He becomes active as a child at his age should be; he starts to speak and laugh. Back home he is admitted at a regular primary school in his commune.

The teacher reports that when she first got him in her class, she was confused on how to teach him and stop other children teasing him with his leg. She was invited to the Support Centre to have a short on-the-job training course which focused on how to support Y An. After the training course she made an individual education plan for Y An and received support from a teacher at the Centre to implement the plan. Y An now counts and writes, he has been evaluated to be cognitively good compared to his peers.



Even though we realise that successful Inclusive Education is more than enhancing access to education, we have no quantitative data on how the quality of education provided to the children with special education needs in an inclusive setting has improved. We have however many stories of change that illustrate this change (see box 2 for an example).

## Conclusion

To address the multiple needs of CWD it is important to apply a comprehensive approach to offer diverse rehabilitation services. Access to quality education services is a human right, but not always easy to realise in a context where the education system is still meeting many challenges. This article describes a comprehensive CBR programme in the Central Highlands of Vietnam, with a focus on the Early Intervention and Inclusive Education component of the programme. We argue that in such a context it is essential to start early, and invest in the comprehensive support system around the CWD and his or her family. Capacity building at human resource, organisational and institutional levels at the same time is vital for a supportive chain to ensure the real inclusion for CWD.

Key contributing factors to the success of programme, are that the education component is part of a comprehensive approach closely linked to the existing education system. An important element of the support system built up around the child is an Educational Support Centre. The Support Centre provides centre based support as well as out-reach support to the child, the parents and the teacher.

The comprehensiveness of the programme is reflected by the diversity of interventions as well as the different levels of intervention: the level of the child, the school, the family, the community, and the (education) system level.

Further the programme applied a twin-track approach in two ways:

1. The programme combined *child focused interventions* with *system focused interventions*, from the assumption that change is needed at both levels. The system interventions were considered key following the vision that it should not be the child who should fit the system, but that we should focus on changing systems to be able to accommodate the needs of every child.
2. Where possible CWD were included in the *mainstream education system* receiving optimal support to respond to their special education needs. For some children with more substantial special needs, the strategy was to

support them in a *special education setting* for some time. This usually happened at young age with strong involvement of the parents, who were at the same time instructed on how to support their child at home.

## Notes

- 1 For example by training, coaching and exposure visits as well as support for policy development

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**Zusammenfassung:** In den von WHO, ILO und UNESCO veröffentlichten Richtlinien zu Community Based Rehabilitation (CBR), ist Bildung einer von fünf Bereichen. Es gibt immer noch viel zu lernen, wie diese Richtlinien in der Praxis umgesetzt werden können. Dieser Artikel stellt die Erfahrung eines CBR Programms vor, das in den zentralen Hochebenen von Vietnam unterstützt wird. Der Fokus dieses Artikels ist die frühe Intervention und die inklusive Bildung in dem Programm. Es wird argumentiert, dass ein umfassender Ansatz sowie die Bildung eines differenziereten Unterstützungsnetzwerkes auf verschiedenen Ebenen essentiell ist, um auf die verschiedenen Bedürfnisse von Kindern mit Behinderung und ihren Familien zu antworten.



**Résumé:** L'OMS, l'OIT et l'UNESCO ont publié les directives concernant Community Based Rehabilitation (CBR) dans lesquelles l'éducation est une de cinq domaines. Il reste encore beaucoup à apprendre comment on peut mettre en œuvre ces directives. Cet article présente l'expérience d'un programme CBR soutenu dans des hauts plateaux du centre du Viêt Nam. Cet article se concentre sur l'intervention précoce et sur l'éducation inclusive dans le programme. On y argue qu'une approche compréhensive et la formation d'un réseau de soutien diversifié à différents niveaux sont essentielles pour répondre aux besoins divers des enfants handicapés et de leurs familles.

**Resumen:** La educación es una de las cinco áreas en la línea directriz para la Rehabilitación Basada en la Comunidad (RBC), que fue publicada por la OMS, la OIT y la UNESCO. Todavía hay lecciones que aprender cómo se aplican estas orientaciones en la práctica. Este artículo describe las experiencias de un programa de RBC en las

tierras altas centrales de Vietnam, que se centra en la intervención temprana y la educación inclusiva. El éxito tiene un enfoque integral. En este caso, la construcción de una red de múltiples facetas de los partidarios es esencial para responder a las diferentes necesidades de los niños con discapacidad y sus familias.

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# Community Based Rehabilitation: A Strategy for Promoting the Rights of Young People with Disabilities in Rural and Indigenous Communities in Oaxaca, Mexico

Flavia Anau

Community Based Rehabilitation is a strategy hampered in its implementation by the vision of care prevailing in our societies, particularly in Mexico. The Piña Palmera experience is a shared experience and has a 28-year development behind it that reflects the diversity and multidisciplinary nature of its approach in the same timely manner as well as expressing the specific rural and indigenous aspect of the challenges and the alternatives involved.



Figure 1: Piña Palmera A.C.

Piña Palmera Centro de Atención Infantil, A.C. is a non-governmental organisation (NGO), legally constituted with no political or religious interests, which has been tackling for more than 20 years the issue of persons with disability of all ages from rural communities, the majority of whom are indigenous people. Piña Palmera is working on the southern coast of Oaxaca in the areas of rehabilitation, social integration, information and prevention of disability (physical, mental or behavioural), regardless of the grade of disability, financial circumstances or ethnicity.

In 1989, Piña Palmera contacted the PRO-JIMO project in Sinaloa, founded by David Werner. This brought us at Piña Palmera for the first time in contact with a model of rehabilitation based in the community. David Werner's experience in the north of Mexico inspired us to find

out more about this new approach, as our region in the south of Oaxaca is very rural and local communities are very isolated from one another. Therefore, it is not feasible to work with a strategy that does not take this context into consideration. For this reason Piña Palmera began in 1994 with the first CBR programme using the WHO manual, *Training in the community for people with disabilities*.

This article describes the work of Piña Palmera and the knowledge that has been gained in the last few years through the work of volunteers from many different countries, Mexican students and local personnel.

## The Path to Community Based Rehabilitation (CBR) in Oaxaca

To start the CBR programme, the community should acknowledge the need for the programme through a parent or other family member, a student, a teacher, or other community member. We, the Piña Palmera team, evaluate the need in a community based on factors such as transportation available, accessibility, geographic placement and the interest in the programme that different actors in the community demonstrate.

The team visits communities where it presents information about CBR. Through some simple questions about conditions in the community, persons with disabilities and the services available in the community, we start a diagnostic together with the authorities in the community.

We take care that all persons with disabilities (PWDs) participating in the programme are included in family life and immersed in their social and cultural environment. The factors that impact their development as persons are their social network, culture, and the local perception of a disability. These are the initial aspects of the community diagnostic.



## The First Steps

The initial diagnostic is made during various visits to the community in which Piña Palmera has an initial meeting with the people that are interested in the programme, local authorities and other community actors. Our experience has taught us that it is better to leave the responsibility for calling the meetings to the local authorities. Sometimes they invite us to participate in their regular assemblies.

In the first meetings we start to determine the conditions and situations in which PWDs live in the community. We survey existing services, communication media, transportation, local culture, local economy, economic sectors, and we always stress the participation and the responsibility of the community. This work is done very practically by observing realities and interacting with community members.

The themes that are discussed in the subsequent community meetings focus on observations about the living conditions of PWDs. We also introduce distinctions between disabilities and sicknesses, and between rehabilitation and cures. We use our organisational learning to enrich the diagnostic, which is always growing and changing with our experience working with PWDs and communities.

All of the information obtained through the diagnostic is evaluated within Piña Palmera's holistic rehabilitation team. Based on the community context, we then decide whether to implement the CBR programme in the community or not. If the decision is negative we will inform the contact person in the community and invite them to join another community already working with CBR.

Another important part of this first contact with the community is the sensitising and consciousness-raising workshop series in which we simulate different disabilities and hold collective reflection sessions with teachers, local authorities, medical personnel, students, and other community actors. The goal of the workshop series is to promote acceptance and inclusion of PWDs and to promote the participation of people and groups that do not have disabilities like teachers, students and taxi and bus drivers.

To reach more people in communities, we regularly distribute information through local radio stations on health, disability and human rights topics in both Spanish and the local language of Zapotec. In these broadcasts, family members also participate along with PWDs and others.

## Joining Alliances: The Importance of Being a Community

We create community assistance networks in which local authorities, medical personnel, teachers, PWDs, their families, and religious authorities participate. Each network is different for each community. Each person in the network has a specific responsibility in accordance with their level of influence in the community, their activities and their position. The network helps us among other things to complete a comprehensive census of the PWDs in their communities including outlying farms; make appointments for patients and their families to meet with the CBR team of Piña Palmera; capacity-build in basic techniques of rehabilitation; prevent and detect deterioration in disabilities; and socially integrate PWDs. For the census we use an open questionnaire with simple questions about their disability, the problems they face, and the ones they have solved. To implement physical rehabilitation and language therapy, the network uses space and material made available by the community. The network is a tool to promote the participation of the different sectors that make up the community and from there consolidate the spaces in which the PWD and their families participate. It is the responsibility of all members of the network to integrate the outlying farms with the town centre to make the CBR programme accessible to everyone. The community diagnostic, the sensibility and consciousness workshops and the creation of the community assistance network all form what we call the process of social rehabilitation. The process creates a space for discussion, reflection and action around the theme of disabilities, ties together the social reality in which PWDs live, and promotes changes for the PWDs within their family and the environments in which they develop.

The rehabilitation of PWDs and their families is part of a system of value in which the Piña Palmera team reviews a person's nutritional deficiencies, challenges to movement, language, learning, and aural functions together with their family. Goals are defined in accordance with the local realities and limitations. The goals are very concrete, realistic, and time-bound. Based on these goals, a therapist advises rehabilitation promoters (family members or not) on basic rehabilitation techniques using local materials.

The local rehabilitation promoters are people from the community, whether a family member or someone else who is interested in participating in capacity building. In addition to



engaging in the programmes of therapy with the PWDs, they are also responsible for promoting the participation of other families and other community actors. The promoters are also responsible for protecting the human rights of the patients and their families as they coordinate with the different community participators.

Due to the great demand in the area and the fact that there are few or no services that respond to the needs of the PWDs, we also work with the private and government sectors. We enjoy direct relationships with different institutions both private and governmental, at national and international levels that work in health, education, sports and culture, among others. We have had the opportunity to guide their focus in their work with PWDs. This synergy has been done gradually and carefully with the governmental sector that in Oaxaca has historically been isolated from the work of NGOs, especially in rural areas.

### **To See, Capacity-Build, Evaluate... and Celebrate**

Piña Palmera's team educates promoters on basic techniques of rehabilitation and success is evaluated together with the families and/or promoters and the PWDs. We have discovered from experience that it is very difficult to maintain the progress of the rehabilitation if the family is not committed to our system of creating collective spaces with families and incorporating the experiences of the PWDs that have already been rehabilitated through our programme.

In our interactions with parents, family members and community promoters, we attempt to communicate clearly and concisely so that we are understood in the culture in which we work. We must be conscious of our limits and not be tempted to give answers when in reality we don't have any, but rather attempt to investigate further. To promote continuity, Piña Palmera's team supervises the process of rehabilitation with the PWDs and their families. This supervision happens in the communities in a collective manner, evaluating achievements in accordance with the goals established at the beginning of the process, accessibility needs, and obstacles they have encountered from re-adjusting goals along the way. If the PWDs have finished the process of rehabilitation, we orient and educate them and their families in more advanced concepts of inclusion and ability development. The rehabilitation process is a set of actions that favour the development of the abilities of PWDs beyond simple rehabilita-

tion, and is the essence of the work from a social approach. One result has been the provision of adequate access to public spaces in communities where CBR works, such as parks, cultural centres, and pedestrian bridges, to ensure equal opportunity for PWDs to participate in the population, which has no disabilities.

The possibility of inclusion for PWDs at school or in work is evaluated together with their family members according to their disability and rehabilitation progress. In many situations, if the disability is not severe, inclusion is promoted from the beginning of the process of rehabilitation. For example, a child has problems walking, or talking, or has a psychological problem or is undernourished. We provide this child with a specialist doctor a neurologist, or geneticist, or an orthopaedic doctor, always in agreement with the family, and only then when they are ready to make their own decision. There are no specialist doctors in the communities where we work, they are mainly in urban areas and in hospitals in some cities, and we accompany the PWDs when they require treatment of this type. The information requested is given so that they themselves can understand the situation and make the decisions that seem most adequate. The responsibility and decisions are always theirs. However, we have found it to be true that to reach any goal in the process of rehabilitation, it is necessary that the family provides continuity in the rehabilitation activities at home. We utilise simple language and we find activities that can be done inside the everyday family dynamic involving personal hygiene, collective cleaning of the house, growing plants and food, etc. If the family speaks an indigenous language we find someone to help us translate. As part of our methodology, every six months we evaluate the progress of the programme and we make changes necessary in the areas of rehabilitation, social integration, consciousness-raising, capacity building of the promoters and family members, and the themes for local radio. Together with the communities, we finish the participant evaluations by completing questionnaires and group reflections with the parents of the family, the PWDs and anyone else participating in the community assistance networks.

An important part of our methodology is the parent working groups and the community assistance networks, which share experiences, successes, obstacles and alternatives to solutions in the processes of rehabilitation. Our CBR strategies were constructed based on our own experiences, described in the introduction, building on conversations with national and in-



ternational organisations, and have grown from reacting to obstacles we have encountered, successes we have enjoyed, and listening to the contributions of people already rehabilitated through our programme. In the last 20 years, about 5000 PWDs and their families and seven local authorities have participated in our programme.

We frequently tie the programme of CBR together with workshops on sexuality and gender studies, sports events in wheelchairs, and camps in which we organise activities to develop independence, socialisation and skill training.

### Interview with Mariano, a Young Blind Man Who is Now Part of the Team of CBR Facilitators

1. How have you progressed in your process of rehabilitation? What activities have you engaged in?

I have definitely developed more skills. At first I was very insecure and I was scared to move around to different places. After 11 years, I feel safer and I can do more activities. When I started at Piña, the workshops helped me to have more confidence and develop as a person. For example, one activity in the centre's store consisted of attending to customers and being in charge of sales. Also talking on the radio about themes of disability and sensibility workshops got me to talk about my experience. I also have educated other people in Braille, independent living and taught teachers to pay more attention to inclusion at their schools.

2. How has your family reacted to your process of rehabilitation? What things changed? How did they help you?

My family has changed a lot. At first they were scared that something was going to happen to me because I was only 13 years old. But later they realised I could do many things and didn't need so much protection. It took time for them accept my disability, but now they have absolute confidence. They helped to bring me to Piña so that I could learn Braille and how to use a walking stick. They also brought me to school so I could continue my education.

3. How has your community changed in respect to your process of rehabilitation? Does your community discriminate against you?

My community does not discriminate against me now because they know that I can do everything I want to. They have changed their attitudes. My neighbours used to help me return to my house when I got lost and in school they helped me stay included. In my community they

motivated me to keep moving forward, they helped me when I went out alone and, in turn, I would educate them on topics related to disabilities. I talked about these topics in different meetings we had. After I informed the community, they knew I could do many things alone. I have since helped in representing my neighbourhood. My job has been to help find resources necessary for the construction projects in the community.

### Conclusion

CBR is a powerful strategy for PWDs and their families living in isolated communities or who do not have services for their rehabilitation and inclusion processes. It is a tool that understands and recognises disability as an issue of discrimination. It is a progressive, participatory approach and generates responses to the challenges faced by PWDs and their families from their contexts. It involves all community stakeholders, creating strengths within communities and social groups, linking and strengthening the social fabric of the community itself. CBR connects, transforms and recreates community spaces and relationships, builds values and changes paradigms.

"We seek to create a world where it is less difficult to love..." Paulo Freire

**Zusammenfassung:** *Community Based Rehabilitation ist eine Strategie, deren Implementierung durch die karitative Sichtweise erschwert wurde, die in unserer Gesellschaft, speziell in Mexiko vorgeherrscht hat. Diese 28-jährige Erfahrung und Entwicklung, die die Verschiedenheit und multidisziplinären Tätigkeiten innerhalb dieser Zeit reflektiert und unsere Herausforderungen und Alternativen von einem ländlichen und indigenen Blickpunkt beschreibt, wird von der Organisation Piña Palmera geteilt.*

**Résumé:** *Community Based Rehabilitation était une stratégie dont sa mise en œuvre est rendue difficile par la vision dominante dans notre société, surtout au Mexique. L'expérience de Pina Palmera est partagée et a connu un développement de 28 années qui reflète la diversité et les activités multidisciplinaires et qui décrit nos défis et alternatives d'un point de vue rural et indigène.*



**Resumen:** *La Rehabilitación Basada en la Comunidad fue frenada en su implementación por la visión caritativa que prevalecía en nuestras sociedades, en particular en México. Estas experiencias fueron el punto de partida de un desarrollo de 28 años de nuestra organización Piña Palmera, que representa la diversidad y la multidisciplinariedad en el primer plano. El artículo describe y refleja nuestros desafíos y alternativas desde un punto de vista rural e indígena.*

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## Kurzmeldungen/Announcements

### BMZ veröffentlicht Aktionsplan zur inklusiven Entwicklungszusammenarbeit

Am 6. Februar 2013 hat die Parlamentarische Staatssekretärin im Bundesministerium für wirtschaftliche Zusammenarbeit und Entwicklung (BMZ), Gudrun Kopp, den Aktionsplan zur Inklusion von Menschen mit Behinderungen in der Entwicklungszusammenarbeit vorgestellt. Der vorgelegte Aktionsplan ist laut BMZ nachhaltig angelegt und soll die deutsche Entwicklungszusammenarbeit strukturell inklusiv gestalten.

Der Aktionsplan beinhaltet drei Handlungsfelder mit mehr als 40 Einzelmaßnahmen. Mit dem ersten Handlungsfeld zielt das BMZ darauf ab, selbst inklusiv zu werden. Daneben geht es in den weiteren Handlungsfeldern darum, die Inklusion von Menschen mit Behinderung in ausgewählten Programmen in Partnerländern umzusetzen sowie in die Zusammenarbeit mit internationalen Entwicklungsakteuren, der Zivilgesellschaft und Wirtschaft einzubringen. Vom Verband Entwicklungspolitik deutscher Nichtregierungsorganisationen (VENRO) wird der Aktionsplan grundsätzlich begrüßt, wenngleich die konkrete und verbindliche Umsetzung angemahnt wird.

**Information:** [http://www.bmz.de/de/publikationen/reihen/strategiepapiere/Strategiepapier325\\_01\\_2013.pdf](http://www.bmz.de/de/publikationen/reihen/strategiepapiere/Strategiepapier325_01_2013.pdf).

### BRK-Allianz veröffentlicht Parallelbericht

Am 21. März 2013 wurde der Parallelbericht der BRK-Allianz *Für Selbstbestimmung, gleiche Rechte, Barrierefreiheit, Inklusion* veröffentlicht. Die BRK-Allianz besteht aus 78 Organisationen der Zivilgesellschaft, die die Umsetzung der UN-Konvention über die Rechte von Menschen mit Behinderung kritisch begleitet.

Während sich der überwiegende Teil des Parallelberichts mit der Umsetzung in Deutschland beschäftigt, gibt es auch einen Berichtsteil zur Umsetzung der *internationalen Artikel* (Artikel 11 und 32) der Konvention. Wie auch bei der Umsetzung im nationalen Kontext werden hier zahlreiche Defizite aufgezeigt. Der vollständige Bericht wie auch weitere Informationen sind auf der unten aufgeführten Website zu finden.

**Information:** <http://www.brk-allianz.de/index.php/m-nachrichten.html>.

### Incheon Strategy to Make the Right Real for Persons with Disabilities in Asia and the Pacific

Governments of the ESCAP region gathered in Incheon, Republic of Korea, from 29 October to 2 November 2012 to chart the course of the new Asian and Pacific Decade of Persons with Disabilities for the period 2013 to 2022. They were joined by representatives of civil society organisations, including organisations of and for persons with dis-

abilities. Also in attendance were representatives of inter-governmental organisations, development cooperation agencies and the United Nations system. The Governments at the High-level Intergovernmental Meeting adopted the Ministerial Declaration on the Asian and Pacific Decade of Persons with Disabilities, 2013–2022, and the Incheon Strategy to Make the Right Real for Persons with Disabilities in Asia and the Pacific. The Incheon Strategy provides the Asian and Pacific region, and the world, with the first set of regionally agreed disability-inclusive development goals. Developed over more than two years of consultations with governments and civil society stakeholders, the Incheon Strategy comprises 10 goals, 27 targets and 62 indicators. The Incheon Strategy builds on the Convention on the Rights of Persons with Disabilities and the Biwako Millennium Framework for Action and Biwako Plus Five towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific.

The Incheon Strategy will enable the Asian and Pacific region to track progress towards improving the quality of life, and the fulfilment of the rights of the region's 650 million persons with disabilities, most of whom live in poverty. The ESCAP secretariat is mandated to report every three years until the end of the Decade in 2022, on progress in the implementation of the Ministerial Declaration and the Incheon Strategy.

**Information:** <http://bit.ly/134Hpn4>, <http://www.unescap.org/publications/detail.asp?id=1523>.

### New Module on Child Functioning and Disability

The Convention on the Rights of the Child (1989), and the Convention on the Rights of Persons with Disabilities (2006) focus on the disparities faced by children with disabilities and call for improvements in their access to services, and in their participation in all aspects of life. In order to achieve these goals, there is a need for improved data collection internationally. The current lack of accurate, cross-nationally comparable data impedes the development, implementation and evaluation of policies and programmes that would improve the lives of children with disabilities.

Recognising the lack of internationally comparable data on child functioning and disability, the Washington Group on Disability Statistics (WG – a UN sponsored City Group commissioned in 2001 to improve the quality and international comparability of disability measures) and UNICEF are collaborating on the development of a survey module that will address the need for current and relevant data to meet that need.

The UNICEF/WG Survey module reflects current thinking on child functioning and disability and is based on the conceptual framework of the WHO International Classifi-



cation of Functioning, Disability and Health for Children and Youth (ICF-CY). Focusing on functional limitations, the module will identify those children at risk of social exclusion and reduced social participation within a country in, for example, family life or education. Furthermore, the UNICEF/WG collaboration aims to develop a survey module on child functioning and disability that would produce cross-nationally comparable data and promote the harmonisation of such data. The UNICEF/WG module covers children aged 2 - 17 years old and assesses basic activity domains including communication, hearing, vision, learning (cognition and intellectual development), mobility, emotions and behaviors. The module also includes aspects of developing relationships and playing. These more complex domains may involve the organisation of coordinated activities or skills including hand/eye coordination, communication, and mobility, among others. The ability of a child to develop relationships and play (whether alone or in the company of others) is considered as a building block to the further development of social skills.

The module has undergone cognitive testing in a few countries (India, Belize and USA), with more cognitive testing planned (Oman and Montenegro). Upon the completion of cognitive and field testing, the module will be made available for countries to use in household surveys and censuses.

UNICEF is also working on the development of a standardised methodology for a more in-depth assessment of disability in children. This will consist of data collection protocols and assessment tools, as well as a framework for the analysis of findings. Recognising that high-level specialists may be in short supply in some areas, a toolkit is being designed to enable trained mid-level professionals, such as teachers and community workers, to administer the new methodology. This will serve to strengthen local capacity to identify and assess children with disabilities.

Information: [http://unstats.un.org/unsd/statcom/statcom\\_2013/seminars/Disability/default.html](http://unstats.un.org/unsd/statcom/statcom_2013/seminars/Disability/default.html), <http://www.addc.org.au/content/resources/unicefwashington-group-on-disability-statistics-module-on-child-functioning-and-disability/937/>

## A Disability Inclusive Development Agenda Towards 2015 and Beyond

On December 3<sup>rd</sup> every year, the world celebrates the International Day of Persons with Disabilities with the purpose of increasing awareness and understanding of the rights of persons with disabilities. The International Disability Alliance (IDA) joins the celebration of this day and takes the opportunity to appeal to the international community to address the discrimination and exclusion faced by persons with disabilities by including persons with disabilities in the post-MDGs framework.

In the last years there has been significant progress in recognising and proactively addressing the exclusion and discrimination faced by people with disabilities, as evi-

denced by the Millennium Development Goals (MDGs) Summit outcome document (September 2010), which highlights the need for inclusion of persons with disabilities and the outcome document Rio+20 (2012), which recognises the participation of persons with disabilities in the development agenda. However, the reality is that persons with disabilities are still excluded from policies and programmes aimed at achieving the MDGs.

An inclusive and accessible new post-MDGs framework would support persons with disabilities in their daily struggle against discrimination and poverty and would empower them to have an active say in choices affecting their lives, in line with the principles of dignity, autonomy and participation enshrined in the Convention on the Rights of Persons with Disabilities (CRPD). "The international community has to mainstream disability in the post-MDGs processes, acting consistently with the CRPD" stated Yannis Vardakastanis, IDA's Chair "The High Level Meeting on Disability and Development to be held in September 2013 should lead to an increased attention to the rights of persons with disabilities in the post-MDGs international development framework and the participation of persons with disabilities through their representative organisations will be a key element to achieve a disability-inclusive development agenda."

## Nigerians with Disabilities Lack Access to Education

The Nigerian Centre for Citizens with Disability (CCD) reports that over 80% of Nigerians with disabilities lack access to formal education. The Executive Director, CCD, Mr. David Anyaele, argued that the difficulty persons with disabilities face in getting formal education was due to minimal access to public infrastructure. Less than 0.1 per cent of the schools in Nigeria have facilities for persons living with disabilities. "Because access is beyond ramp and lifter to enter classes, it includes accessible toilets, library for people who are blind and sign language interpreter for students who are deaf to mention but a few. These have made it extremely expensive to train a child with disability with formal education." Anyaele added that CCD and similar organisations have made submissions to the National Assembly to establish their rights in the ongoing constitution review.

Information: <http://www.punchng.com/news/15m-physically-challenged-nigerians-lack-access-to-education/>.

## Executive Board Draft Resolution Calls for Better Health Care for People with Disabilities

At its 132nd session, World Health Organisation's (WHO) Executive Board adopted a draft resolution on disability that will be debated at the World Health Assembly in May this year. The resolution endorses the recommendations of the World report on disability and calls for WHO and Member States to ensure equal access to health services



for persons with disabilities. The draft resolution urges States Parties to implement the Convention on the Rights of Persons with Disabilities (CRPD), develop plans of action, and ensure that mainstream health services address the needs of people with disabilities. The resolution also requests further action on improving disability data, strengthening health systems for the provision of rehabilitation and assistive technologies, and enhancing Community Based Rehabilitation. The resolution constitutes an important step in preparations for the High-level Meeting on Disability and Development (HLMDD).

**Information:** [http://www.who.int/disabilities/media/news/2013/25\\_01/en/index.html](http://www.who.int/disabilities/media/news/2013/25_01/en/index.html).

### My World: The United Nations Global Survey

MY World is a United Nations global survey asking you to choose your priorities for a better world. There are 16 priority areas in the survey, plus one more for you to decide, which can be made disability-specific. For example: Freedom to make my own decisions; Being included in the community by removing architectural and attitudinal barriers; Including persons with disabilities in all development plans, programmes and activities. You decide! Results will be shared with world leaders in setting the next global development agenda. People with disabilities from all over the world are invited to participate and to share this survey with others.

**Information:** <http://enable.myworld2015.org>.

### Say Yes to Inclusion!

In preparation for the High-level Meeting on Disability and Development (HLMDD) on 23 September 2013, the End Exclusion project (funded by Light of the world) hopes to generate worldwide support for the inclusion of persons with disabilities in development initiatives. Persons with disabilities are frequently excluded from the fight against poverty. In many parts of the world, persons with disabilities don't have access to education, employment or health services. It's time to change this! Everybody has the right to get an education and a job, be able to access health care and have a say about their lives.

In the new international action, people are invited to show their support for the inclusion of persons with disabilities in the fight against poverty.

The campaign would like to motivate people to learn to say "yes" in sign language and to publish their photos or videos of this on their website to show the support that End Exclusion has for their fight for Inclusion.

**Information:** [j.blijkers@light-for-the-world.org](mailto:j.blijkers@light-for-the-world.org), [www.endexclusion.eu](http://www.endexclusion.eu).

### International Networking Site for Disabled Youth Launches

International Network for Disabled Youth, known as INDYspace an online network dedicated to connecting young disabled people aged 16-30 from around the world, has been officially launched. The website, funded by Oxfam Australia through their Oxfam International Youth Partnerships (OIYP) programme, is the first of its kind in bringing young people with disabilities together on a global level. It enables users to sign up and share their experiences through the posting of blogs, pictures and videos, as well as providing information on a range of relevant topics including disability rights, independent living, travel and transport, and inclusion and accessibility, acting as both a network and an information base to which users can contribute. It is hoped that in the long term, the site can provide informative, user-run webinars and interactive online video conferences. There is a strong dedication to making the site both ascetic and accessible to its users, with recommendations given by a web accessibility consultant currently being implemented. The founders of the website, Erin Gough from New Zealand and Zara Todd from the United Kingdom, who first met at an Oxfam international youth conference two years ago, embody the site mission of enabling young disabled people to work together across borders, constructing the site from opposite sides of the globe. When asked why the pair created the website, Zara Todd commented „We saw that there was a gap, online and literally within the international sector for young disabled people to connect to one another. We wanted a way for young people with disabilities to all become stronger, to enable them to find solutions together to the barriers that they face as young disabled people, regardless of what country they're in.“ Erin Gough added that the site was „made by young disabled people, for young disabled people“ and that she hoped users would take the opportunity to both use and share the site, as „the more of a global force we are, the more global change will be created“.

**Information:** [www.indyspace.org](http://www.indyspace.org), [www.facebook.com/indyspace](http://www.facebook.com/indyspace); E-Mail: [info@indyspace.org](mailto:info@indyspace.org).

### New Enable Webpage on Indigenous Persons with Disabilities

The UN Department of Economic and Social Affairs (DESA) has prepared a new web page to draw attention to issues related to indigenous persons with disabilities. While no global data exists regarding indigenous persons with disabilities, available statistics show that indigenous peoples are disproportionately likely to experience disability in comparison to the general population. Indigenous persons with disabilities often experience multiple discrimination and face barriers based on their indigenous status, as well as their disability. The international community has also recognised that special measures are required to protect the rights of the world's indigenous peoples. This web page will continue to develop as a hub of news, resources



and links related to indigenous persons with disabilities.

**Information:** <http://www.un.org/disabilities/default.asp?id=1605>.

## WHO - JPMH Mental Health and Human Rights: Call for Papers

The Journal of Public Mental Health (JPMH) announces a call for papers for a special issue on mental health and human rights, to be published in 2013. Accepted contributions include original research papers, systematic reviews, policy analyses and case studies. In 2012, the World Health Organisation (WHO) Department of Mental Health and Substance Abuse launched the QualityRights (QR) Project, which aims to improve the quality and human rights conditions in mental health and social care facilities and empower civil society organisations to advocate for the rights of people with mental and psychosocial disabilities. This call for papers aims to inform the core objectives of QualityRights. JPMH hopes to attract papers from academics, practitioners and activists in resource-scarce countries. Papers submitted for this special edition should be marked with "QualityRights" in the title. The manuscript selection process will follow the Journal's peer-review procedures.

**Information:** [http://www.who.int/mental\\_health/publications/QualityRights\\_toolkit/en/index.html](http://www.who.int/mental_health/publications/QualityRights_toolkit/en/index.html) submit articles: <http://emeraldinsight.com/products/journals/journals.htm?id=jpmh> (before 1 June 2013), E-Mail: [Leeknifon@gmail.com](mailto:Leeknifon@gmail.com).

## Ausstellung: 20 Jahre Anti-Landminenkampagne - Für eine minenfreie Welt

Die Ausstellung würdigt das 20-jährige Bestehen der Internationalen Kampagne für das Verbot von Landminen. Außenminister Guido Westerwelle eröffnete sie im November im Auswärtigen Amt, die nächsten Stationen sind die UNO in Genf und New York.

In Anwesenheit von knapp 200 geladenen Gästen hielt Minister Westerwelle die Eröffnungsrede der gemeinsamen Ausstellung von Handicap International, medico international SODI und vom Auswärtigen Amt. Er würdigte damit das jahrelange Engagement der Internationalen Kampagne zur Ächtung von Landminen und dankte allen, die sich der Sache verbunden fühlen. Die Ausstellung zeigt großformatige Fotos, aufgenommen von den namhaften Fotografen Till Mayer, John Rodsted, Sean Sutton und Lukas Einsele in jenen Ländern, die am meisten von der Minen- und Blindgänger Gefahr betroffen sind, außerdem Kunstobjekte der Künstlerin Shirin Homann-Saadat

und des Konzeptkünstlers Peter Zizka. Wer sich auf den künstlerischen Blick einlässt, erahnt etwas von der schrecklichen Realität jener Minenfelder, die in vielen Regionen der Welt das Leben von Menschen beeinträchtigen und gefährden. Begleitende Texttafeln dokumentieren den Beginn und die Höhepunkte der Internationalen Kampagne für das Verbot von Landminen, die 1997 mit dem Friedensnobelpreis ausgezeichnet wurde und von Kofi Annan als die „erfolgreichste Bürgerinitiative der Welt“ bezeichnet wurde. Die Kampagne, die in der Ausstellung stellvertretend von drei der beteiligten Organisationen vertreten wird, ist ein Symbol dafür, dass zivilgesellschaftliche Initiativen tatsächlich globale Politik gestalten und reale Veränderungen erreichen können.

Die nächsten Stationen der Ausstellung sind nun jeweils die UNO Gebäude in Genf und New York.

**Information:** <http://www.handicap-international.de/landminen/news-detailansicht/article/ausstellung-20-jahre-anti-landminenkampagne-fuer-eine-minenfreie-welt-485.html>, <http://www.medico.de/media/begleitheft-zur-ausstellung.pdf>.

## „Ich war ein ‚normales‘, aber ein besonderes Kind“ - bezev veröffentlicht Lebensgeschichten von Menschen mit Behinderung aus aller Welt

Eine Milliarde Menschen leben weltweit mit einer Behinderung. Über 80 % davon in den sogenannten Entwicklungsländern. Doch welche persönlichen Geschichten verbergen sich hinter diesen Zahlen? Wie wachsen Menschen mit Behinderung in anderen Ländern auf? Welche Möglichkeiten und Herausforderungen haben sie in ihrem Leben? Um diese Fragen zu beantworten, hat bezev sechs Menschen aus Afrika, Asien und Lateinamerika zu Wort kommen lassen und ihre Antworten auf seiner Homepage veröffentlicht.

„Ich war ein ‚normales‘, aber doch auch ein besonderes Kind, das von einer sinnvollen Arbeit träumte. Diese Arbeit sollte nicht nur mein eigenes Leben verbessern, nein, ich wollte auch einen Beitrag zur Verbesserung und Entwicklung meiner Gemeinde und meines Landes leisten.“, erzählt zum Beispiel Abdul Quahir aus Afghanistan, der sein Bein durch eine Mine verlor. Andere Teilnehmende, wie Sawarat aus Thailand, erzählen, wie sie sich in ihrem Land in Selbstvertretungsorganisationen engagieren und welche Herausforderungen sie für Menschen mit Behinderung sehen. Die Interviews sind zum Nachlesen und oder als Video mit Untertitel verfügbar.

**Information:** [www.bezev.de](http://www.bezev.de).



## Literatur

### *International Society for Prosthetics and Orthotics (ISPO)*

#### **Prosthetics and Orthotics Impact Assessment Report in East Africa**

As part of its United States Agency for International Development (USAID) funded programme Rehabilitation of Physically Disabled People in Developing Countries, and building on past work, ISPO studied the impact of training personnel to the minimum standards ISPO Category I & II and conducted a partial audit of graduate clinical skills and competencies.

**Bezug:** [http://www.ispoint.org/sites/default/files/archives/prosthetics\\_and\\_orthotics\\_impact\\_assessment\\_east\\_africa\\_minimum\\_size.pdf](http://www.ispoint.org/sites/default/files/archives/prosthetics_and_orthotics_impact_assessment_east_africa_minimum_size.pdf).

### *Centre for Human Rights of Persons with Disabilities*

#### **Disabilities, Human Rights and International Cooperation: Human Rights-Based Approach and Lived Experiences of Ugandan Women with Disabilities**

This study investigated human rights-based approaches of international and development cooperation towards the equality of persons with disabilities in Uganda. A case study method as well as a participatory research approach among others was applied to create evidence-based and in-depth knowledge on the theme, particularly from the viewpoint of women with disabilities and deaf women on the grassroots level.

**Bezug:** <http://bit.ly/VKchsU>.

### *Lorraine Wapling/Bruce Downie*

#### **Beyond Charity: A Donor's Guide to Inclusion**

This easy-to-read guide supports donors to address disability from a human rights perspective, in particular by supporting Disabled People's Organisations (DPOs). This guide is divided into four main parts. Part I provides basic information on the background to the Convention on the Rights of Persons with Disabilities (CRPD) and its general principles to help donors place the CRPD in the context of their own strategies. Part II provides examples of practical actions donors can implement that will improve the way funding is promoted and managed so it becomes increasingly inclusive. Part III offers guidance for how donors can engage more directly with representative organisations of persons with disabilities. Finally, Part IV provides examples of disability organisations and links to further information about disability inclusive funding.

**Bezug:** <http://www.disabilityrightsfund.org/donor/donorguide.html>.

### *Human Rights Watch*

#### **Human Rights of Women and Children with Disabilities**

This report highlights various human rights abuses against

women and children on the following topics: sexual and gender-based violence targeted at women and girls with disabilities; discrimination in health and reproductive rights, including forced sterilisation and HIV and disability; barriers to education for children with disabilities; violence against children with disabilities in schools; and abuses in institutions. This resource is useful to anyone interested in human rights of women and children with disabilities

**Bezug:** <http://www.hrw.org/news/2012/09/11/human-rights-women-and-children-disabilities>.

### *Inclusion International*

#### **Inclusive Communities = Stronger Communities**

The Inclusion International's Global Report on Article 19 confirms that most adults with intellectual disabilities live at home and do not have the support they need to live and be included in their communities. It reveals that families are the major source of support. The report highlights that transforming communities to be inclusive and ensuring that people with disabilities are included in mainstream programmes are essential for securing the rights of people with intellectual disabilities.

**Bezug:** <http://www.inclusion-international.org/wp-content/uploads/Global-Report-Living-Colour-dr2-2.pdf>.

### *United Nations (ESCAP)*

#### **Disability at a Glance 2012: Strengthening the Evidence Base in Asia and the Pacific**

The Disability at a Glance series, which started in 2006, serves as a companion for policymakers, statisticians and representatives of organisations of, and for, persons with disabilities in Asia and the Pacific. These publications aim to provide a regional overview of disability policies and practices, as well as relevant country data and information.

The fourth edition, Disability at a Glance 2012: Strengthening the Evidence Base in Asia and the Pacific continues this tradition. It highlights the complexity of interpreting disability data and stresses the urgent need to work towards a greater common understanding of disability, related data and data collection practices.

**Bezug:** <http://bit.ly/S5t5cL>, <http://www.unescap.org/publications/detail.asp?id=1521>.

### *Pan African Network of People with Psychosocial Disabilities (PANUSP)*

#### **African Psychosocial Disability Watch**

In December 2012, the Pan African Network of People with Psychosocial Disabilities (PANUSP) launched the first edition of a newsletter entitled the African Psychosocial Disability Watch. The newsletter aims to promote information sharing at a regional and international level so as to strengthen solidarity and raise awareness of the issues, challenges and progress of people with psychosocial disabilities in Africa.

**Bezug:** <http://www.panusp.org/wp-content/uploads/2011/10/African-Psychosocial-Disability-Watch-2012.pdf>.



### *Office of the High Commissioner for Human Rights (OHCHR)*

#### **Thematic Study on the Work and Employment of Persons with Disabilities**

The study prepared by the Office of the High Commissioner for Human Rights (OHCHR) focuses on the work and employment of persons with disabilities and analyses relevant provisions of the Convention on the Rights of Persons with Disabilities (CRPD). In its resolution 19/11, the Human Rights Council had requested OHCHR to prepare the study in consultation with States and other relevant stakeholders, including organisations of persons with disabilities, and national human rights institutions. The study highlights good practices in promoting employment opportunities for persons with disabilities, and identifies the main challenges that States parties encounter in ensuring that persons with disabilities enjoy access to, retention of and advancement in employment on an equal basis with others.

**Bezug:** <http://www.ohchr.org/EN/Issues/Disability/Pages/StudyonWorkandEmploymentofPersonswithDisabilities.aspx>

### *Light for the World Netherlands/Enablement/Athena Institute (Vrije Universiteit Amsterdam)/Dutch Coalition on Disability and Development*

#### **Count Me In. Include People with Disabilities in Development Projects**

Persons with disabilities are among the poorest in the developing world and are often left out of development projects. This often happens because development organisations simply do not know how to include them. Count Me In. Include People with Disabilities in Development Projects is a practical guide that offers suggestions and useful tips on how to launch inclusive programmes and projects, how to prepare staff working with persons with disabilities and how to adapt your organisational processes and systems.

**Bezug:** <http://www.dccd.nl/todo/make-your-programs-inclusive/>.

### *Sport for Development and Peace*

#### **Harnessing the Power of Sport for Development and Peace: Recommendations to Governments the Power of Sports – Chapter 5: Sport and Persons with Disabilities: Fostering Inclusion and Well-Being**

This report is the result of the SDP IWG's initial four-year mandate (2004-2008) and presents evidence of the effectiveness of Sport for Development and Peace. The report demonstrates that well-designed programmes that prioritise the best values of sport can drive development goals forward. It presents:

Consolidated up-to-date evidence of sport's effectiveness as a development agent in key thematic areas health and disease prevention, child and youth development, gender empowerment, inclusion of persons with disabilities, and peace-building; specific policy recommendations for government sectors working in these areas; and practical and cross-cutting policy recommendations to all ministries within national governments on how to integrate sport as

a tool for development and peace into national and international development policies and programmes.

The report is also available in French and Spanish.

**Bezug:** <http://bit.ly/sgTmaG>, <http://www.righttoplay.com/International/news-and-media/Documents/Final%20Report%20revised%202010.pdf>, <http://www.righttoplay.com/International/news-and-media/Pages/PolicyReports.aspx>.

### *Leonard Cheshire Disability (LCD)*

#### **Inclusive Education – An Introduction**

Leonard Cheshire Disability (LCD) has recently published "Inclusive Education – An Introduction". Every child in the world has a right to education. However, children with disabilities are still disproportionately excluded from school. In an inclusive school, disabled children do not study in separate classes; all children learn together in the same classroom using materials appropriate to their various needs. This publication explores LCD's approach to inclusive education and highlights their projects in Africa and Asia that support children with disabilities to get the education that they, and all children, deserve.

**Bezug:** <http://www.lcint.org/?lid=5136>, <http://www.lcint.org/download.php?id=1031>.

### *Hesperian Foundation*

#### **A Health Handbook for Women with Disabilities**

Women with disabilities often discover that the social stigma of disability and inadequate care are greater barriers to health than the disability itself. This Handbook, developed with the help and experience of women with disabilities in 42 countries, can help women with disabilities overcome barriers, improve their general health, self-esteem and ability to care for themselves, as well as increase their participation in their communities.

**Bezug:** [http://en.hesperian.org/hhg/A\\_Health\\_Handbook\\_for\\_Women\\_with\\_Disabilities](http://en.hesperian.org/hhg/A_Health_Handbook_for_Women_with_Disabilities).

### *Cesvi/Handicap International*

#### **Children with Disabilities in Somaliland: A Knowledge, Attitudes and Practices Household Survey**

This household survey by Cesvi and Handicap International looks at the knowledge, attitudes and practices in Somaliland toward children with disabilities. Children with disabilities face acute protection issues in Somaliland. These issues range from lack of education to high incidence of sexual violence. Tying up children with disabilities is common practice throughout the country and in some areas children with disabilities may be denied food. Despite the critical nature of the situation, little research has been performed on the needs and vulnerabilities of children with disabilities in Somaliland. This survey, conducted by Cesvi and Handicap International with funding from the EC, aims to address part of this gap.

**Bezug:** [http://www.cesvi.org/aaa-root/o/Children%20with%20disabilities\\_Somaliland2013.pdf](http://www.cesvi.org/aaa-root/o/Children%20with%20disabilities_Somaliland2013.pdf).



## VERANSTALTUNGEN/EVENTS

- 06.06. - 07.06. M-Enabling Summit 2013, Washinton DC.  
**Information:** <http://www.m-enabling.com>, Kontakt: E.J. Krause & Associates, Inc., 6430 Rockledge Drive, Suite 200, Bethesda, MD 20817. Michael Rosenberg, E-Mail: [rosenberg@ejkrause.com](mailto:rosenberg@ejkrause.com), Tel.: 301-493-5500, ext.3308 or G3ict – Global Initiative For Inclusive Technologies, Francesca Cesa Bianchi, Tel: 678-534-8518, E-Mail: [fcesabianchi@g3ict.org](mailto:fcesabianchi@g3ict.org).
- 27.06. - 28.06. Symposium on Disability, Technology and Rehabilitation in Low and Middle Income Countries, Washington.  
**Information:** <http://idtr.uwctds.washington.edu/workshops/2013>, Kontakt: Becky Matter, Project Analyst of International Initiatives Centre for Technology & Disability Studies, University of Washington, E-Mail: [bmatter@uw.edu](mailto:bmatter@uw.edu) or Mark Harniss, Clinical Associate Professor Rehabilitation Medicine, University of Washington E-Mail: [mharniss@uw.edu](mailto:mharniss@uw.edu).
- 02.07. - 03.07. Include 2013: Global Challenges and Local Solutions in Inclusive Design, Hong Kong.  
**Information:** [www.hhc.rca.ac.uk/4989/all/1/include-2013.aspx](http://www.hhc.rca.ac.uk/4989/all/1/include-2013.aspx), Kontakt: The Helen Hamlyn Centre for Design, Royal College of Art, Kensington Gore, London SW7 2EU, UK, Tel.: 044-20-7590-4242, Fax: 044-20-7590-4244, E-Mail: [hhcd@rca.ac.uk](mailto:hhcd@rca.ac.uk).
- 09.09. - 11.09. 6th International Urban Design Conference, Sydney.  
**Information:** <http://urbandesignaustralia.com.au>, Kontakt: Conference Secretariat, The Conference Office, C/o AST Management Pty Ltd, PO Box 29 Nerang, QLD 4211, Tel.: 617-5502-2068, Fax: 617-5527-3298, Email: [conference@urbandesignaustralia.com.au](mailto:conference@urbandesignaustralia.com.au).
- 20.09. Beschäftigung und berufliche Bildung, Köln.  
**Information:** Institut für inklusive Entwicklung; Wandastr. 9, 45136 Essen; Tel.: 0201/17 89 123; Fax: 0201/17 89 026; E-Mail: [info@inie-inid.org](mailto:info@inie-inid.org)
- 03.10. - 05.10. 6. Symposium Internationale Heil- und Sonderpädagogik  
Die UN-Behindertenrechtskonvention – Umsetzung und Auswirkungen weltweit, München.  
**Information:** <http://www.edu.lmu.de/sechstes-symposium/index.html>, Kontakt: Ludwig-Maximilians-Universität München, Leopoldstraße 13, D-80802 München, Tel.: 0049-89-2180-5117, Fax: 0049-89-2180-6320, E-Mail: [6.Symposium@edu.lmu.de](mailto:6.Symposium@edu.lmu.de).
- 16.10. - 18.10. 2nd International Conference of the World Federation of the Deaf (WFD), Sydney.  
**Information:** [www.wfdsydney2013.com](http://www.wfdsydney2013.com), Kontakt: ICMS Pty Ltd, PO Box 170, Hawthorn VIC 3122, Australia, Tel.: 1300-792-466, Fax: 0061-3-9818-7111, E-Mail: [wfdsydney2013@icms.com.au](mailto:wfdsydney2013@icms.com.au).
- 01.11. - 02.11. Workshop: Wie soll die Welt von morgen aussehen? Zukunftsfähige Entwicklung inklusiv gestalten, Köln.  
Information: Behinderung und Entwicklungszusammenarbeit, Wandastr. 9, 45136 Essen; Tel.: 0201/17 88 963; Fax: 0201/17 89 026; E-Mail: [kampagnen@bezev.de](mailto:kampagnen@bezev.de); [www.bezev.de](http://www.bezev.de)
- 29.11. - 30.11. Tagung: Globales Engagement im Unterricht mit Kindern mit Behinderung und im gemeinsamen Unterricht. Haben wir nicht andere Probleme?  
Information: Behinderung und Entwicklungszusammenarbeit, Wandastr. 9, 45136 Essen; Tel.: 0201/17 88 963; Fax: 0201/17 89 026; E-Mail: [inklusion@bezev.de](mailto:inklusion@bezev.de); [www.bezev.de](http://www.bezev.de)
- 03.12. Menschenrechte, Behinderung und Entwicklungszusammenarbeit  
**Information:** Institut für inklusive Entwicklung; Wandastr. 9, 45136 Essen; Tel.: 0201/17 89 123; Fax: 0201/17 89 026; E-Mail: [info@inie-inid.org](mailto:info@inie-inid.org)



## Schwerpunktthemen kommender Ausgaben der Zeitschrift Focal Topics of Upcoming Issues

- 2/2013: Von CBR zu Community Based Inclusive Development, Teil 2/From CBR to Community Based Inclusive Development, Part 2 (verantwortlich/responsible: Sabine Schäper)
- 3/2013: Inklusion in der Entwicklungszusammenarbeit/Inclusion in Development Cooperation (Arbeitstitel) (verantwortlich/responsible: Gabriele Weigt)
- 1/2014: Diskriminierung überwinden/Overcoming Discrimination (verantwortlich/responsible: Jana Offergeld)

Interessierte Autorinnen und Autoren mögen sich für nähere Informationen und unseren *Leitfaden für AutorInnen* bitte an die oben genannten Verantwortlichen wenden. Darüber hinaus sind Vorschläge für weitere Schwerpunktthemen willkommen unter [info@inie-inid.org](mailto:info@inie-inid.org).

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### Deadlines for the upcoming issues:

	2/2013	3/2013	1/2014
Hauptbeiträge/Focal articles	15.05.2013	15.08.2013	15.11.2013
Kurzbeiträge/Other contributions	15.06.2013	15.09.2013	15.01.2014

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