

# International Encyclopedia of Rehabilitation

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Center for International Rehabilitation Research Information and Exchange (CIRRIE)  
515 Kimball Tower  
University at Buffalo, The State University of New York  
Buffalo, NY 14214  
E-mail: [ub-cirrie@buffalo.edu](mailto:ub-cirrie@buffalo.edu)  
Web: <http://cirrie.buffalo.edu>

*This publication of the Center for International Rehabilitation Research Information and Exchange is supported by funds received from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133A050008. The opinions contained in this publication are those of the authors and do not necessarily reflect those of CIRRIE or the Department of Education.*

# **Towards Greater Independence: Handicap International Celebrates 25 Years of Contribution to the Field of Rehabilitation**

**Luc Pariot, Masseur-Kinésithérapeute, M.Sc.**

## **Introduction**

Handicap International (HI) is taking action for people with disabilities in the developing world. Over the years, the organization has developed an expertise in several areas such as emergency situations, rehabilitation and global mine action, physical and mental health, as well as inclusion and promotion of disability rights and policies. This article will mainly address the HI contributions to the field of rehabilitation. To address this question, the article begins with an overview of the HI organization, followed by a discussion about the situation of people with disabilities in developing countries. Next, the concept of rehabilitation as well as various approaches will be illustrated by reviewing some of the initiatives that HI has taken since more than 25 years. Handicap International has adapted to the various environmental settings and helped disability supporters in their change process by providing training, new technologies, outreach, and appropriate methodologies. The goal of this article is thus to review cases of projects in order to get an overview of the rehabilitation practices in developing countries and their implications. While this article is not intended to be exhaustive in the review of HI rehabilitation projects, some other articles are available in recent experience information documents. Most of the information used in the writing of this article comes from websites of the Handicap International network (<http://www.handicap-international.org>), various field experiences of the author, as well as many internal documents. Otherwise, the reference is indicated.

## **Overview of the organization – Historical perspective**

Handicap International is a non-profit humanitarian organization focused on the issue of disability. Since the creation of the French organisation in 1982 in Lyon, six European and two North American sections (Canada and United States) were created. It acts in empowering and managing nearly 250 field projects. Each section of Handicap International is involved in the process of managing the actions carried out in the field as a part of a globally-managed program network. In 1997, Handicap International was a co-winner of the Nobel Peace prize for their work to ban landmines. Work to set up an international federation began in 2003, and it is expected to be created by 2009.

It was in Thailand in 1982 that two French physicians had the idea to create the organization. Their first mandate was to provide humanitarian relief to Cambodian refugees living in temporary camps along the Thai-Cambodian frontier. The first orthopedic centers were created around that period, and the simple and available material used were assets in helping the organization to both provide immediate, tangible and efficient assistance, and to form qualified local work teams. A quarter century later, the organization has set up programmes in more than 60 countries, and continues to respond to humanitarian needs in Thailand and Cambodia.

Handicap International carries out emergency and development projects. It also takes action in support of disability advocacy in the international political arena. Their actions boil down to:

- promoting the rights of persons with disabilities and inclusive development (Inclusive development is the process of ensuring that all persons with disabilities are included at every phase of the development of their rehabilitation program in order to consider their specific needs. Translated excerpt from Pauline Restoux. *Le handicap et la solidarité internationale*, 2008) (at the international, European and national levels);
- fighting against the use of landmines and cluster bombs (e.g. victim assistance, Mine Risk Education programs (MRE), mine clearance, etc.);
- developing rehabilitation and psychological support services (e.g. prosthetic and orthotic devices and training of professionals);
- preventing the onset and progression of disabling conditions (e.g. diabetes and HIV/AIDS);
- providing support to partners for their projects (e.g. social and economic integration project, disability sports, community-based rehabilitation or CBR), and;
- strengthening the capacity of civil society to advocate and influence public policies through empowerment and self-determination approaches (e.g. supporting the implementation of the UN Convention on Rights of Persons with Disabilities in collaboration with Disabled People Organizations (DPOs).

### **Fighting exclusion**

Handicap International takes action in some of the poorest countries in the world. Marginalization of persons with disabilities or their exclusion from development programs contributes to aggravate poverty and deny the fundamental rights of individuals. Persons with disabilities as well as populations affected by chronic or disabling conditions do not have access to appropriate services. The health care system of those countries does not consider disability, so millions of persons with disabilities do not have access to appropriate medical care, rehabilitation, social services, economic integration, education and social participation.

### **Prevalence statistics**

- Around 10% of the population worldwide, or 650 millions of individuals, live with a disability. They are the world's largest minority (UN). This number is increasing through population growth and the ageing process. Moreover, it is not only the concerned person who is affected by disability, but also his or her family (loss of income, exclusion, poverty).
- 80% of persons with disabilities live in developing countries (UNDP)
- Only 45 countries have anti-discrimination and other disability-specific laws.
- 90% of children with disabilities in developing countries do not attend school (UNESCO).
- The illiteracy rate for adults with disabilities is of 97% and of 99% for women with disabilities (UNDP).
- The World Bank estimates that 20 per cent of the world's poorest people live with disabilities.
- 80% of persons with disabilities in developing countries live on far less than \$1 a day (Helsinki University, 2005)
- Unemployment among persons with disabilities is as high as 80% in developing countries. Often employers assume that they are unable to work (ILO).
- Women with disabilities are recognized to be multiply disadvantaged, experiencing exclusion because of their gender and their disability.

- 80% of persons with disabilities living in developing countries are excluded from HIV/AIDS prevention programs. Only 3% of the world's persons with disabilities obtain any form of education about HIV/AIDS.

## **The concept of rehabilitation**

Rehabilitation is the health care provided to people with permanent or temporary disabilities in order to help them learn to overcome their disabilities. “Disability” means a loss of ability to perform personally meaningful and/or socially valued activities due to one or more health problems (WHO, 2001). « Rehabilitation’s goal is to restore the physical and mental health of individuals, and consequently increase their social participation in all daily life activities. This is why rehabilitation interventions (kinesitherapy/physical therapy, training with mobility aids, education on how to take care of the disabled body) provides a good foundation to further support persons with disabilities in their self-management with regard to their educational, vocational, and social life—this is re-integration » (Pauline Restoux, 2008).

## **Rehabilitation approaches**

Following the Second World War (B.Gobin, Du modèle à la pratique, HI, mars 2000) and the increased number of people with disabilities, rehabilitation has been made a priority in industrialized countries. As a result, many institutions were created with professionals and rehabilitation experts. Because implementing institutionalization and expertise had required significant human and financial investment, two other types of systems were created: mobile rehabilitation teams and community-based rehabilitation. They are not a substitute to the institutional system, but they help filling gaps and are closer to the individual’s life environment. HI is thus taking actions at three different levels of the rehabilitation field in collaboration with various partners:

- Institutional rehabilitation: persons with disabilities come to the health care unit and are provided with services, exercises, training etc.
- Mobile rehabilitation teams: they emerge from the 1<sup>st</sup> level as they come from services. Rehabilitation professionals travel to various peripheral or local health care centers to assist persons with disabilities in their own life environment. Handicap International has acknowledged that it is often difficult to access services in large urban communities of several countries and is thus promoting the development of outreach services (home support), which are closer to people. It is often difficult for rehabilitation centers to support the costs associated with these operations.
- Community-based rehabilitation (CBR): strategy integrated within general community development (cf. definition in next section). This approach is complementary to the other two levels of care and addresses the issue in an integrated, cross-cutting, and global fashion. It is cheaper and based on sustainable development and long-term viability of actions.

As mentioned above for many injured individuals or persons fitted with prostheses, independence often involves relearning to accomplish every activity of daily living. Health professionals, whether kinesitherapists/physical therapists, occupational therapists, speech therapists or psychomotor therapists, play a crucial role in the individual’s long recovery process, but their number is generally inadequate in countries where they are most needed. In order to correct these shortcomings, Handicap International's teams support certified training programs for trainers, through which these professionals can become independent practitioners in the places where they are critically needed. Topics covered in training include

disability, CBR, management, projects of development of medicalized, educative and/or social structures, Disability Creation Process (DCP), tailored interdisciplinary intervention plan/program, etc.

## **Commitments and evolution of practices: health, provision of care and rehabilitation have been HI's main priorities ever since its creation**

At HI, rehabilitation is regarded as the first steps towards independence. Each rehabilitation project should initially be adjusted to individuals' various life courses, and to the local, technical and professional capacity. Following a request from the authorities of the partner country or in response to a funder's tender, HI develops training and support policies concurrently with direct actions at the beginning of the intervention to assist local actors in building long-term capacity.

Persons with disabilities are provided with physical and mental care enabling them to pursue the life-long projects they value:

- Improved health care and rehabilitation services to persons with disabilities;
- Follow-up by the health care and rehabilitation centers (development projects, certification approaches, service delivery management);
- Training and support for health professionals (initial training and continuing education, executive training, support to the creation of professional networks);
- Information, awareness, education about the prevention of diseases and disabilities;
- Environmental hazard prevention.

The particularity of HI is that it takes action essentially involving the building of capacity for local partners who work in health care institutions (hospitals, rehabilitation centers, health care centers) or at the community level. HI provides them with assistance, but does not replace them (except in emergency programs). Each HI project leader is responsible for operational implementation, transfer of skills, budget monitoring, team management, relationships with partners and local authorities, as well as project and report writing. HI teams promote the use of interdisciplinary interventions and give priority to training and expertise sharing. The organization also values the use of local resources and techniques, partnership with teachers, health care personnel, close family, local organizations, political bodies or economic actors to ensure that everyone is part of a large solidarity network.

## **Emergency response, personnel replacement and long-term sustainable development project**

The following are a few examples of projects representing the various types of actions carried out by HI, from emergency situations to sustainable development:

In January 2005, Handicap International launched an emergency intervention in Indonesia to provide the need on kinesitherapy/physiotherapy requirements for tsunami survivors. As a result, this emergency response initially included dispatching health care teams within seven hospitals distributed among three urban agglomerations affected by the natural disaster (Banda Aceh, Meulaboh, Sigli). Very quickly, this personnel replacement action—hospital personnel was mostly absent during the first weeks and then progressively reintegrated their services—was transformed into a long-term training project in collaboration with two

kinesitherapy/physical therapy schools of the province and professionals working in local hospitals. This partnership also enabled HI to develop projects related to fitting by supporting national amputee assistance initiatives and the school of orthopedic technicians based on the island of Java.

Handicap International began its work in Sierra Leone in 1996 following the urgent need of appropriate services and resources for the specific situation of upper limb amputation. Since 2000, the organization has stabilized its actions and progressively shifted from emergency program delivery to sustainable development actions. As of today, these mainly focus on psychological treatment for war survivors, and most particularly for former child soldiers and street children, and in the field of physical rehabilitation through appropriate training of orthopedic technicians and kinesitherapists/physical therapists. The organization also provides the material and equipment required to make prostheses and orthoses.

In Djibouti in 1991, HI worked under the Ministry of Public Health and Social Affairs to the setting up of fitting and functional rehabilitation workshops within a hospital for persons with physical disabilities. The organization also decentralized its activities, and transferred responsibilities to the providers of Djibouti's peripheral areas. HI has contributed, among others, to the implementation and reorganization of a new rehabilitation center, as well as kinesitherapy exercise rooms in peripheral health centers, and to the training of seven kinesitherapy assistants. HI also organized sessions to raise awareness on the issue of disability in Djibouti's nursing school, primary and secondary schools, took part in a national seminar on rehabilitation, and supported and coached the Djibouti's sports club for people with disabilities.

In 1990, HI intervened in Romania following an exploratory mission highlighting the urgent needs of children in orphanages. Rehabilitation specialists worked in collaboration with orphanage staff (e.g. in Slobozia and Giurgiu) to reinforce their capacity. They contributed to the reform of the operations in these institutions and to the training of tutors to ensure a better management of the children with psychomotor retardation (e.g. basic kinesitherapy/physical therapy exercises along with educational games).

These examples are representative of the diversity of interventions and approaches used by HI over the years in extremely different settings.

### **The concept of community-based rehabilitation (CBR)**

Handicap International has worked in the field of CBR since the 1990s. "Through its actions for persons with disabilities of the developing world, HI became implicitly involved in CBR" (*Un constat, la RBC et HI*, C.Berti et P.Chervin, 1998). HI has worked in several countries through rehabilitation programs (training of orthopedic technicians or kinesitherapy assistants in rehabilitation facility settings) and was concerned with the quality of the patient referral and follow-up systems following their visit or inpatient stay. At the end of the 1980s, WHO implemented CBR pilot projects in about ten countries in the world and HI had common partners who were oriented towards a community approach of rehabilitation in order to improve the quality of life of persons with disabilities in the very environment where they live.

Community-based rehabilitation or CBR is "a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with

disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services.” (“CBR joint position paper,” ILO, UNESCO and WHO 2004)

This definition reflects the shift of CBR from a home-based care approach to a community development approach. “It promotes social participation and communities manage the HI programs. It recognizes that persons with disabilities should have access to the same services as the rest of society, such as healthcare services, child healthcare programs, social services, and education. It also takes into consideration the role of persons with disabilities and their organizations as resources to reinforce CBR programs.” (“CBR joint position paper,” ILO, UNESCO and WHO 2004)

Handicap International also became in favor of the CBR approach and implemented several projects in Mali, Thailand, Nepal, Bangladesh, Vietnam, Congo, Rwanda, Cuba, Colombia and Cambodia. Back then, every HI community-related project or project related to the decentralization of rehabilitation care was more or less classified under CBR. Initially, HI had worked in the CBR field in accordance with the anchor or entry points it had developed ever since its creation, often through medical approaches such as fitting workshops, rehabilitation centers paramedical professionals and little emphasis was put on the contextual and social aspects.

For instance, HI has been involved from 1994 to 1997 in a CBR intervention in Vietnam in collaboration with three institutions in three different provinces. Along with its Vietnamese partners, the organization has planned training sessions for community workers who would in return ensure follow-up of persons with disabilities in their own environment. Training sessions of several weeks focused on changing attitudes towards persons with disabilities, on basic functional rehabilitation exercises, follow-up after fitting, and on the making of assistive products with the available local materials. Handicap International has simultaneously developed kinesitherapy and prosthesis fitting referral centers, took action in the other sectors (social, education, employment, creation and reinforcement of disability advocacy organizations) and finally attended provincial, national and international seminars on CBR. In 2009, these projects were still underway, technically and financially managed by Vietnamese partners. Actions lead in villages were as simple as making bamboo parallel bars to help in training gait in children, wooden seats to help children taken their meals or follow up a person fitted with an orthosis.

Since 1998 in West and Central Africa, HI has also been supporting with the provision of training and the assessment of several projects within the community, whether they were projects of rehabilitation care decentralization, project implemented by ministries, non-governmental organizations (NGOs) or community development organizations. HI has contributed in the networking of these various experiences through a journal and seminars in order for its partners to share their expertise and improve their practices.

Over time, and with the modification of intervention strategies, the CBR strategy initially developed showed significant evolution and shifted in new directions. In order to illustrate the current orientation of CBR, as defined by the WHO as an integrated strategy of community development, one experience of Handicap International can be mentioned. This experience started in Bangladesh in 1997 in collaboration with the local organization *Centre for Disability in Development* (CDD). Together, they developed the Community Approach to Handicap in Development (CAHD), which aims at assisting international development

organizations to integrate rehabilitation and people with disabilities in their activities. This approach has also been developed in Nepal, the neighbouring country where HI provides support and training to about thirty local community development organizations in disability-related issues, and inclusion of disabled people in their development process. A study of CBR activities and projects in Nepal was conducted at the request of the Government. This study will provide recommendations on future governmental policies, the recognition of a legal career path for rehabilitation community workers and the creation of a centralised information system.

### **“Standing tall” with assistive products: orthoses, prostheses, technical aids, wheelchairs**

Orthosis: a device that supports a paralyzed or weakened limb

Prosthesis: a device that replaces the limb or the missing part of the limb

It is through fitting that HI has developed new products that are adapted to various environmental settings.

“The number of personnel estimated to be needed to provide services in prosthetics and orthotics to the millions of people in Southern countries would be around 180,000 professionals (estimated in 2005 by WHO). However, there are few schools that could train personnel, and each year, they graduate no more than 400 personnel qualified in some measure to make and fit prostheses and to teach patients how to use them. In some countries like Niger, no prosthetist/orthotist professional is available. It should be remembered that 80% of persons with disabilities live in Southern countries. The poorest individuals who have motor disabilities are forced to live without orthopedic devices that could change their lives. In 2010, the estimated number of people in need of prosthetic and orthotic devices in Africa, Asia and Latin America will be 30 millions. However, the majority of them cannot have access to prostheses or orthoses (splints, braces, etc.) because of the level of poverty” (Translation of the text from the French HI’s website: <http://www.handicap-international.fr>)

Handicap international works in countries where the lack in terms of prosthetic and orthotic devices lead the population to seek for local solutions with the help of “crafty do-it-yourselfers” who can make prostheses or other orthopedic devices with the materials available locally: bamboo, tin cans, old tires, wood, aluminum sheets, recycled plastic and even shell cases. Users or craftsmen can thus perform repairs locally. What is important is that people using these devices can walk and work so that they no longer are a burden on their family.

In this setting of persons with disabilities’ life and environment, HI has developed an appropriate technology with local materials and available infrastructures, with respect to biomechanical data, to make prostheses, orthoses and other types of assistive products (crutches, walkers, wheelchairs) in order to meet the needs. Whether in Djibouti, Cambodia or West Africa, HI has contributed along with small companies to make wheelchairs from wood or metal. The organization also works in close partnership with local health care systems to set up recognized training programs for orthopedic technicians and support the creation of orthopedic centers. There is thus no ultimate technical solution to meet the needs of these users. The setting in which every fitting device is prescribed, as well as the local availability of materials, human resources, training opportunities and the capacity of monitoring people using these devices are all factors that should be considered.

In the 1990s, in Cambodia for instance, the main goals of HI was to implement fitting workshops, provide training to prosthesis/orthosis technicians and to make these workshops work independently, that is without external assistance. In the Pursat province area, HI has implemented an fitting workshop for which 900 amputees were reported. Handicap International supervised the fitting workshop activities in close partnership with provincial authorities. Cambodian technicians were provided with pretraining in Phnom Penh under the supervision of HI's technicians. In only two years, Cambodian technicians have shifted from the use of the "leather/wood" technology (making of leather and wooden prostheses) to the polypropylene technology. At first, provincial technicians were working without electricity, using only a plane, try square and hand drill. Their work was still consistent with biomechanical rules. Handicap International provided a power generator to the workshop in order to promote technological change. However, this new equipment did not seem to be adequate for all pioneers in plastic design. They would often come back to the workshop to make leather prostheses because they were easier to repair locally. HI also worked with the Ministry of Social Action and the provincial hospital to improve the quality of those devices, raise awareness of the population on them, train technicians, manage the workshop, as well as to build and install a workshop appropriate to the needs of persons with disabilities (amputees). One of the goals was to lead the workshop towards greater independence by taking action in the technical, administrative and financial areas. HI expanded the Pursat workshop in 1992 in order to increase production and improve the quality of service delivery to patients. The workshop now includes a machine room for the thermoforming oven, a mould room, a room to work on the positive mould and proceed with finishing, as well as a stock room, office, dormitory, kitchen and gait training path. One Cambodian company that handcrafts foot prostheses uses a technology that was itself implemented in collaboration with HI.

Until now, the organization has implemented knowledge and technology transfer projects along with local structures, similar to the ones implemented in Cambodia, but also in Mozambique and Angola, to make a prosthetic foot made of vulcanized rubber (oven cured). This foot has undeniable and validated dynamic qualities, and consistent with cosmetic requirements and local skin color. This is a good example of the role of HI in the development of varieties of orthopedic components via direct skills and technology transfers to developing countries.

Handicap International intervenes in emergencies regarding amputees (for instance after the 1988 earthquake in Erevan, Armenia). The organization has emergency kits available today to fit amputees with prostheses through the existing network of professionals:

- Below-knee prosthesis sockets made with acrylic resin strips, or adjustable standard models of above-knee prostheses in polypropylene (thermoformed plastic);
- Use of a modular prosthetic assembly to simplify the work of prosthesis/orthosis technicians and ease lives of patients. The result is making the prosthesis as light as possible and easy to adjust.

Since 2005, HI's coordination of orthopedic services has set up a prosthetic and orthotic component recycling project. This project is based on a network of fitting workshops in the Rhône-Alpes area in France and on the contribution of volunteers working to recycle these components. Devices received are sorted then disassembled. Prosthetic and orthotic components in good condition are sanitized, refurbished and put into plastic pouches prior to storage. Beneficiaries of these point-to-point shipments are HI programs and their local

partners, such as the *Ecole Nationale des Auxiliaires Médicaux* of Lomé, Togo or the *École Polytechnique* of Solo in Indonesia. Both these institutions train prosthesis/orthosis technicians and sometimes experience funding difficulties regarding educational materials to facilitate technology transfer or vocational practice courses. In 2006, shipments of recycled components were also sent to schools that provide training for prosthesis/orthosis technicians in Togo, Indonesia, Philippines and Benin (via the student association of the Lycée Montplaisir in Valence). To access these recycled components, HI programs or its local partners need to meet a number of criteria. This project is carried out with ethics and proper framework to avoid “garbage shipments” that are frequently occurring in developing countries. The purpose is thus to ensure that this material is really needed in the location where it is sent, and that it will be used in proper conditions. This project is also environment-friendly. In fact, only the components may be exported to developing countries. Synthetic substances, major component of orthopedic devices, are extracted and treated in France” (excerpt translated from the French HI’s website: <http://www.handicap-international.fr>).

### **Contribution in terms of research**

Several members of the HI team acquired academic training and experience in the field of rehabilitation research. As such, the organization developed competencies to deal with its various mandates such as literature review on specific topics, study on needs, development and validation of tools, and research in terms of prosthetic/orthotic devices.

An illustration of this are the R&D activities (Research & Development), which aim at developing new orthopedic device fabrication procedures that are consistent with local resources, and the economic and social development of a given country. HI specialists can perform mechanical and clinical testing of new orthopedic device prototypes prior to considering wide-scale distribution (example: making of prototypes using orthopedic components in Indonesia). With these new appropriate technologies, prosthesis/orthosis technicians save time and money and more orthotic/prosthetic devices can be fitted.

### **Capitalization**

Handicap International disseminates its experiences through various means: books, studies, videos, CD-ROMs, articles, newsletters, websites, and via interventions during workshops and seminars. HI’s French section has an information center based in Lyon, which acquired hundreds of documents mainly in French and/or English. HI has gathered on CD-ROMs all the professional products from various sectors that were distributed between 1982 and 2009 (headquarters, field staff, sections).

Since 2002, HI has also worked in collaboration with the Centre for International Health and Development (CIHD) based in London to implement an international information support center on health and disability: <http://www.asksource.info/>

### **Conclusion**

This article gave an overview of the rehabilitation practice carried out in developing countries by an international cooperation NGO over a period of more than 25 years. HI experiences helped to bridge gaps and lead to the creation of partnerships between the North and the South to share knowledge and technological advances. In the face of the extent of international development issues in terms of rehabilitation in difficult political, social and economic settings, HI and its partners were capable of meeting great challenges and suggested practical solutions to enhance the quality of life of persons with disabilities in an innovative manner,

consistent with environmental settings. Also, it is through the hiring of hundreds of expatriate and national rehabilitation professionals that these achievements could be made possible, despite resistance to change in these diversified, inflexible and disorganized socio-political settings going through a state of crisis. There is still a great deal of work to be done, but HI, with more than 25 years' experience, continues to be pushed up by the desire to pursue its mandate while constantly focusing on putting persons with disabilities at the core of its action.

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## **Glossary**

- ILO: International Labour Organization
- WHO: World Health Organization
- NGO: Non-governmental organization
- UN: United Nations
- UNDP: United Nations Development Programme
- UNESCO: United Nations Educational, Scientific and Cultural Organization