Access to services for persons with disabilities in challenging environments
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Whether it’s the provision of prosthetics and orthotics in Cambodia, inclusive education in Burkina Faso, diabetes care in Kenya, psycho-social support in Rwanda, HIV prevention and care in Mozambique, physiotherapy in Albania, post-emergency response in Gaza, community-based disaster risk reduction in India, support to the disability movement in the Middle East or social inclusion for excluded women and men in Afghanistan, Handicap International works to support the development of new and existing services which are accessible for people with disabilities in poor environments, conflict, post-conflict and disaster situations.

From our experience of implementing programmes across 60 countries worldwide, it is clear there is no uniform approach. Our efforts will always be shaped and constrained by the particular institutional, social, political and economic contexts in which we operate. However, there are trends in critical thinking on access to services and divergent examples of practice, upon which it is important to reflect.

In the early 2000’s Handicap International teams in the Balkans began to consider access to services within a broader conceptual framework. This involved thinking about the ideal interplay between regulators, service providers and users, and identifying specific roles and responsibilities for all key stakeholders. This subsequently prompted a shift in programming in the region, from direct service provision for rehabilitation and other social services to an emphasis on capacity building of disabled people’s organisations. From 2006, the primary focus was on systems-level intervention, and specifically, on how service users could influence decision-making about service quality and provision.

While systems-level interventions are not the primary mandate of Handicap International, it is evident that a “systems approach” is necessary to ensure the relevance, quality impact and sustainability of our work. This approach certainly made sense in the Balkans. Economic growth in the region was steady and the State had already assumed its role as regulator, capable and willing to take into account the specific needs of people with disabilities regarding access to services. However, many contexts are not quite so favourable to this transition from direct service provision to a systems-level approach.

These contexts we tend to describe as “challenging”. This refers, in part, to severe poverty and post-conflict environments, but more specifically to government structures and processes that are weak, lacking both the capacity and the political will to allocate resources for the provision and regulation of quality, accessible services. For “challenging” environments, basic health, education and social services often suffer from political neglect, lack of financial resources and a paucity of properly trained and supported service professionals. In such contexts, populations are commonly rural or urban poor, ethnically diverse and lacking the means and capacity to organise themselves as a unified, politically engaged civil society.

In these challenging environments, it is often necessary for Handicap International, as a “practitioner” organisation with a strong experience base at the services level, to engage in direct service provision.

The question of how to improve access to services for people with disabilities has therefore long been the subject of discussion and debate within Handicap International1. In 2009, in order to reconcile some of

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these differences in theory and practice, the Handicap International Technical Resource Division (TRD) launched a comprehensive review of our services projects over the last 10 years. Based on this review, the Board of Directors commissioned a set of operational guidelines to assist teams in strategic planning for effective interventions using a "systems approach" to service development (where no services exist).

These guidelines were studied and enriched by field teams and partners in Amman, Jordan, in December 2009, followed by three days of exchange and debate with international experts. This international seminar was a critical step towards the adoption of systems thinking by Handicap International teams and operational partners.

Handicap International’s regional programme in the Middle East had the great pleasure of hosting an international seminar in Amman from 9th to 11th December on the issue of access to services for people with disabilities. The publication you are holding is an extension of the discussions, feedback on experience and expert opinions heard in the course of the seminar.

The pleasure has in fact been two-fold. Firstly, Handicap International’s team in the Middle-East was proud to continue this region’s age-old tradition of welcome and hospitality in providing this opportunity for experts from dozens of countries and very different horizons to compare their opinions and share their experience. We hope that everyone found the warmth and comfort necessary to their work during these few days.

Finally, Handicap International in the Middle-East was also proud to contribute towards consolidating a theme on which the organisation has been working throughout its 25-year history, and which is also at the heart of our actions here in the Middle-East, where, more than anywhere, there is a need to work on these issues in both stabilised and emergency settings. However, it would seem clear that, whatever the context, common foundations underpin access to services, including both the multi-actor system determining it and notions of rights, accountability and transparency. They constitute the essential basis on which to focus. The experience of our panel of experts, combined with that of Handicap International throughout the world and backed up by wide range of cases making it both tangible and practical, have clearly demonstrated this fact.

We hope that you experience as much satisfaction in reading this publication as we did in welcoming and working with the panel during the seminar.

Susan Girois, MD, MPH, Director, Technical Resources Division

Philippe Chaize, Director of Handicap International’s Regional Programme in the Middle-East
The international seminar held in Amman, Jordan from 9th to 11th December 2009 was made possible thanks to financial support from the Luxembourg Ministry of Foreign Affairs.

Handicap International teams began by analysing a number of projects, discussing their experience and then testing several analysis and programming tools with partners taking part in the seminar. This provided an opportunity to develop a collective vision of “access to services” and to examine the issue from a number of different angles.

The teams then discussed the question of access to services for persons with disabilities in challenging environments with new participants in an open forum. Mr Hubert Seifert of the Association for the Physically Disabled of Kenya (APDK), Dr Mohammed Abu Zayed of the University of Birzeit, Lebanon, Dr Bakht Sarwar of PIPOS, Pakistan, Afrim Maliqi of Handikos, Kosovo, and Karl Blanchet of the London School of Hygiene and Tropical Medicine were among our guests.

This publication contains a collection of short texts presenting comparative and complementary views on access to services for persons with disabilities in challenging environments. It does not attempt to cover the full range of worthy issues for debate in this field that is still far from receiving the attention it deserves, but simply to offer opportunities for reflection on certain themes that we felt it important and pertinent to discuss in light of our current knowledge.

Further work needs to be carried out into certain key areas, in particular the sustainability of access to services, and will be the subject of future publications.

We hope that this publication will help draw the attention and stimulate the efforts this subject so badly needs given the critical human and social issues involved.

Catherine Dixon,
Knowledge Management Unit,
Handicap International
DISABILITY, POVERTY AND ACCESS TO SERVICES

The World Health Organization currently estimates the number of people with disabilities worldwide at around 600-650 million, with as many as 80% living in developing countries. Approximately one in five of those living in absolute poverty are disabled. Disability can be understood as both a cause and a consequence of poverty. Indeed this vicious circle of poverty and disability is today well understood, having been the subject of various research projects and reports.

People living in poverty usually lack access to basic social services, such as health care and education, as well as opportunities for safe employment and proper housing conditions. This exposes them to a high risk of accidents or of developing health problems which can lead to serious illness, injury or impairment. When a person living in poverty acquires an impairment, they face significantly more barriers to accessing health services, education, employment opportunities and other public services. This in turn exacerbates social and economic exclusion and reduces opportunities for moving out of the condition of poverty. The focal point of this vicious circle is not the impairment itself. It is discrimination, social exclusion and the denial of people’s rights, together with a lack of access to basic services that form the primary link between poverty and disability.

7. Axelsson, C. A guidance Paper for an Inclusive Local Development Policy, (Handicap International, SHIA and HSO: 2008): 20. This policy paper was developed as part of a project named “Mainstreaming Disability in Development Cooperation to Break the Cycle of Poverty and Disability in Developing Countries” coordinated by International Disability and Development Consortium (IDDC): [www.make-development-inclusive.org](http://www.make-development-inclusive.org)
ACCESS TO SERVICES AND THE “5 AS”

Taking the right to health as an example (although the following is relevant for all social services), we can make an assessment of access to services based on the following criteria:

- **Availability**: functioning services, where goods and programmes are available in sufficient quantity (services must also be of good quality (see below));

- **Accessibility**: a non-discriminatory approach; accessibility of the physical environment (to include transport and buildings); services being within safe physical reach, including in rural areas; and accessibility of health information and communication;

- **Affordability** (economic accessibility): affordable services for all, health care services as well as services related to the underlying determinants of health (safe and potable water, adequate sanitation facilities...). If payment is required, it is based on the principle of equity;

- **Acceptability**: services are culturally appropriate, respectful of medical ethics and of different values, needs and interests within communities. Sensitive to issues of confidentiality, gender and life-cycle requirements;

- **Accountability**: services and programmes are designed and implemented to respond to the needs and interests of all the community, including marginalised groups. Services actively consult and involve their users (including people with disabilities and their representative organisations) at all stages. Services are “effectively monitored by independent authorities”.

**Quality** is another essential element to be added to “the 5 A’s” which affects them all: services need to be of high quality. In the case of health, they should be “scientifically and medically appropriate”, where quality refers to the competence of the personnel, drugs, medical equipment, water and sanitation, etc.

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8. Some of these definitions are explained in the General Comment 14, Right to health, paragraph 12 by the Committee on the Covenant on Economic, Social and Cultural Rights (CESCR), [http://www.unhchr.ch/tbs/doc.nsf/symbol/40d009901358b0e2c12566915005090be?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/symbol/40d009901358b0e2c12566915005090be?Opendocument)

9. CRPD Article 16 (3), Freedom From Exploitation, Violence and Abuse
Part 1

SOME KEY CONCEPTS AND REFERENCES ON ACCESS TO SERVICES

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One of the specific aspects of the disability service sector is the need for both specialised services and accessible mainstream services at community level. People with disabilities have the same fundamental right to access mainstream services in the community (education, health-care, employment, social services and social protection) as any other citizen.

In order to facilitate access, an additional category of services is often developed in the disability field, known as “support services”. These services aim to increase disabled people’s self-determination and participation in society. Support services help people in their day-to-day activities and participation and are delivered both to people with disabilities and their families. They are key elements for mainstreaming disability and usually include the provision of ortho-prosthetic and assistive devices, personal assistant schemes, support teachers, support people for accessing employment, interpreters for people with sensorial disabilities, accessible housing, etc.

Specialised services are an extended category of services also needed to address the sometimes more complex needs of people with severe/multiple disabilities. They have to be provided in the community on an equal basis, using a person-centred approach, and in a way which respects the choices and the interests of the users and their families. Specific rehabilitation services, residential care in small family-like settings, respite care units, sheltered workshops for severely disabled people, and specialised day care centres for people with very complex needs and dependency, are just a few examples of the services that should be developed at community level to meet the specific needs of people with disabilities.

In emergency situations or conditions of extreme poverty, priority is sometimes placed on ensuring the population’s access to “basic services”. The World Bank and United Nations include services essential to people’s survival in this category (access to clean water, basic foodstuffs, sanitation), as well as education and primary health care, roads and basic security measures.  

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10. “Basic community services and infrastructure notably include: drinking water supply, sanitation, waste management, social protection, transport and communications, energy supply, health care and emergency services, educational establishments, public security and the management of green spaces” (United Nations, Human Settlements Programme, paragraph 84, mentioned in the following document International guidelines on basic access to services for all: http://www.unhabitat.org/downloads/docs/6243_488_K0950029_HSP_GC_22_2_ADD6.pdf)
An inclusive community guarantees access for its citizens to all necessary services and ensures there are no barriers preventing people with disabilities from participating in it social and economic life


A CONTINUOUS AND COMPREHENSIVE SPECTRUM OF SERVICES: TWO KEY CONCEPTS

The spectrum of services required at community level means that a large variety of measures have to be developed simultaneously, in order to respect the rights and address the needs of people with disabilities. The changing and varied needs of people with disabilities throughout their lifetime, mean a wide variety and typology of services are required: from early intervention to educational services, health care and rehabilitation, vocational training and access to employment, day care, housing, support services, leisure and mobility-related services, etc. Each covers a specific part of a person’s life span, enabling them to participate actively in all aspects of socio-economic life.
The *continuity of support* is a key requirement in the disability service sector. It means that, *strong functional and informational links* have to be developed between all the services provided for people with disabilities, thereby allowing the person to benefit from appropriate services at every stage of their life. This requirement is particularly important when passing from one age cycle to another; from primary to secondary school, from childhood to adulthood, from education to employment, from employment to retirement, as well as when the person needs different categories of services simultaneously (such as education and rehabilitation, for example). At these points in time additional specific support services might be required. It is important to take this specificity of the disability service sector into consideration when designing national systems of regulatory procedures for social services.

**THE MAIN ACTORS INVOLVED IN SERVICE PROVISION**

There is a strict relation between access to services and responsibility and good governance: good access to services is assured when the three key stakeholders involve work in close collaboration.

This diagram of the relationship between the different stakeholders should be born in mind when analysing the social services provision process in a country or region. It helps identify the weaknesses and analyse the capacity of each of the stakeholders.

The three key stakeholders involved in the social service provision process are: 11:

- **State actors** (decision-makers) - usually refers to:
  - Central authorities (ministries, central commissions, national cross-sector committees, etc.);
  - Local authorities.

The national public authorities are sometimes replaced or backed up by international bodies when the State is weak or in post-conflict situations.

**The government and decision-makers** assess disabled people’s needs for services and ensure access to these services. The services can be delivered by public service providers or delegated to private organisations; in this case, the government maintains a regulatory role. It defines the main directions and provides the financial resources necessary for ensuring the availability of services, and is also responsible for the quality of services at national and local level.

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11. Many other actors intervene in the process (donors, community, etc.), however these three actors are more significant from the governance (and regulatory) perspective.
The main role of the social services is to compensate for situations of vulnerability, deficit or insecurity, whether temporary or permanent (e.g. social support, home-help for the elderly, soup kitchens, social or psycho-social assistance for large families, etc.). Social services are part of the national social welfare system which, together with financial aids (benefits, pensions, allowances, etc.), form the social security system.

**Service providers** are usually grouped into four categories (*Munday, 2002*):

- Public providers (public agencies, institutions, professionals);
- Not-for-profit organisations providing social services (non-governmental organisations);
- For-profit companies providing services;
- “Informal” providers (such as families or volunteers).

The last three categories are considered as “private providers”.

**Service providers** deliver services which must be of good quality and based on a person-centred approach. They also provide all the information needed by the local and/or national authorities and by the users, and must adhere to defined quality standards and principles. They can take part in tender processes and receive public funds.

A large number of these service providers are non-profit civil society organisations, acting independently, or assuming a public service mission based on a partnership with local or central authorities.

These organisations also have an important role in revealing social objectives, as they often serve vulnerable categories of the population who have difficulty expressing their needs. At the same time they develop a system of knowledge and experience-sharing between people from different environments, as they are looking to make a profit. Finally, they also generate solidarity within the community, as they operate on the basis of voluntary actions and the involvement of the general public.

**Users** of services in the disability sector are:

- People with disabilities (children, adolescents, adults and elderly);
- People with disabilities who are facing multiple vulnerable or at-risk conditions (poverty, gender or ethnic-related discrimination, people affected by HIV and AIDS, people who are exploited or abused etc.);
- Families or legal representatives of people with disabilities.

Users and their family must express their real needs and ensure their choices and priorities are heard. By adopting a proactive attitude, users usually succeed in orienting policies and defend their rights *vis-à-vis* the competent authorities. They receive all necessary information and must keep a critical eye on the quality of services. It is essential for users to be involved in the regular evaluation of existing services.

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12. For example: personal support benefits, transport allowances, personalised budgets, etc.
An effective system of services at community level is only possible when these three categories of stakeholders work in collaboration and fulfil their specific roles:
- expressing their needs and interests in the case of users;
- delivering a qualitative service in case of providers;
- making sure that all legal frameworks support the rights and interests of users and providers – in case of decision makers.

In order to ensure this coherence, States usually put into place a set of so called “regulatory mechanisms”, which make sure that this relationship between actors is formalised and legally defined (through laws, by-laws or implementation procedures).

When States are too weak or unable to fulfill their regulatory obligations (at national or local level and for various reasons, such as lacking the capacity or will to do so), the regulatory role is often “delegated” to someone else: international agencies, local organisations with a neutral perspective in the system, etc. The regulatory procedures make sure that all actors are accountable to each other and that services are delivered in accordance with fundamental rights and quality principles.

REFERENCES


Chiriacescu Diana, de Backer Maryvonne, Botokro Rozenn. Access to services for people with disabilities, Guide for Handicap International teams, Handicap International, September 2010


Experience tends to show that the main factors determining access to services for people with disabilities can be grouped into three main categories, according to whether they are related to the organisation of the services system at local or national level (planning, funding, monitoring, continuous improvement), to the internal management of the services or to the attitudes of users and the population with regard to these services. Many projects for improving access to services for people with disabilities focus either partly or entirely on one or other of these categories. In some cases, although progress can be seen (improvement to physical and financial access, to available information, to referral systems, etc.), the outcomes obtained are constrained by another determining factor that has not been sufficiently taken into account. The relationship between all these different factors is complex, as meeting certain access requirements can sometimes create obstructions elsewhere or, on the contrary, be a prerequisite for meeting others. For example, the population’s perception of the services can be a real barrier to accessing information, in many different ways.

Determining factors are related to:

THE OVERALL ORGANISATION OF THE SERVICES SYSTEM, AT NATIONAL OR LOCAL LEVEL:

- The existence of a sufficient number of services, covering a broad enough spectrum;
- Physical and geographical access to services for people with disabilities, calling for:
  - A geographical distribution adapted to needs across the whole territory;
  - The existence of accessibility standards that are complied with;
- The existence of proximity or community-based services;
- The existence of mobile teams or itinerant services, according to needs;
- Easy transport between the person’s home and the service in question;
- Information on services and benefits widely-disseminated and in multiple formats (braille, sign-language, local languages, easy-to-read, visual, etc.).


- Trained and available professionals (technical training, comprehensive approach and an entrepreneurial spirit) in sufficient number and with a range of complementary skills;
- A reasonable cost and financial accessibility to services;
- Flexible procedures for access to services, not overly bureaucratic and reflecting the users real needs; procedures or services for referring people to appropriate services (Disability Focal Points, state-run disability support centres, referral commissions, etc.).

THE INTERNAL ORGANISATION OF THE SERVICE, AS THE WAY IT OPERATES CAN EITHER FACILITATE OR DISCOURAGE ACCESS:

- Adequate and correctly maintained materials;
- An appropriate range of technologies and available technical aids;
- “Flexible” and adaptable services, using technical means and working methods suited to a wide range of users and to the setting, and capable of responding to changing needs (children who have grown, adults whose treatment requirements have changed, etc.);
- Available information on the prevention and treatment of the diseases concerned (for health services);
- Accurate diagnoses, for the prescription of orthopaedic devices, for example;
- Ease of movement on the service’s premises;
- Quality management focusing first and foremost on the interests of the users and the service’s response to their real needs.

THE ATTITUDE OF THE POPULATION WITH REGARD TO SERVICES OR CARE-SEEKING:

- The care-seeking behaviour adopted by users in looking for and using adequate services, due mainly to knowledge of their rights;
- The awareness and acceptance by all of the importance of access to services for women, minorities, people with disabilities, whatever their impairment, the poor, etc. in order to reduce cultural barriers and those linked to local beliefs or customs.

As part of a national disability survey in Morocco\textsuperscript{15}, “people with disabilities were asked to define which, among the constraints and barriers they are faced with, pose the biggest problems (...)”. Here are the responses given:

<table>
<thead>
<tr>
<th>Constraint</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficient financial means</td>
<td>83.2%</td>
</tr>
<tr>
<td>Geographical distance</td>
<td>25.2%</td>
</tr>
<tr>
<td>Negative image of health-care services</td>
<td>21.1%</td>
</tr>
<tr>
<td>The services have insufficient means</td>
<td>17.6%</td>
</tr>
<tr>
<td>Physical inaccessibility</td>
<td>7.9%</td>
</tr>
<tr>
<td>Communication difficulties</td>
<td>4.6%</td>
</tr>
<tr>
<td>Overly complicated administrative procedures</td>
<td>3.4%</td>
</tr>
<tr>
<td>Lack of information</td>
<td>2.1%</td>
</tr>
<tr>
<td>Other reasons</td>
<td>8.2%</td>
</tr>
</tbody>
</table>

\textsuperscript{15} National Disability Survey in Morocco, Secretary of State in charge of the family, childhood and persons with disabilities, Kingdom of Morocco, with the support of the European Community, 2004
In preparation for the international seminar organised by Handicap International in Amman in December 2009, participants were asked to say what they considered to be the main facilitators for accessing services for people with disabilities:

- Good information and awareness-raising of people with disabilities concerning their rights, available services and the benefits of these services (types, cost, alternatives, etc.);
- Geographic accessibility;
- Low cost of services; existence of “equity funds” or financial and social support systems;
- The good reputation of the service;
- Trained personnel among the service providers;
- Flexible and efficient system for assessing users’ needs and referring them to services;
- Awareness-raising of Disabled Persons Organisations with regard to access to services; training on advocacy and measures for improving the sector;
- Improved social and cultural representations of disability and access to services;
- Public authorities and decision-making bodies in the services sector well-trained in disability issues, the rights-based approach, quality of the offer of service, etc.;
- Mainstreaming of services in national development programmes;
- Coherent legislation at national level in line with the UN Convention on the Rights of People with Disabilities; sufficient funding for services sector;
- Decentralisation of services to bring them closer to users;
- Self-help networks (families, voluntary workers, peer support);
- Improved social participation within the local communities.
USER ACCESS AS PART OF THE SERVICE DELIVERY PROCESS

The quality of access to services by disabled people can not be dissociated from the quality of the services themselves. If the service is well-planned, managed and monitored, the number of people using or asking for it will increase.

To put it briefly, we consider that the service delivery process can be described in the same way as a standard project cycle, via the following phases:

- **Planning** of the intervention;
- **Implementation** of the activities in line with the planning;
- **Evaluation** of the outcomes and the process as a whole;
- ** Corrections, monitoring** and repeat of the process\(^17\).

Good access to services is assured when the whole service delivery process is correctly organised (at local level, within the services system, as well as internally, in each service).

USER ACCESS IS DIRECTLY RELATED TO THE QUALITY OF THE SERVICE

The quality of services for people with disabilities is a comprehensive approach that can be applied to very different socio-economic settings. Improving the quality of a service often results in an improvement to access to this service for disabled people.

There are a number of different quality systems (formulated in terms of principles, standards, or sometimes just quality parameters or indicators) for social services everywhere in the world, and much progress was made in this field between 1990 and 2007.

Bellow are developed three of these reference frameworks:

1. One of the most coherent positions on the quality of services is that of the **European Commission’s High-Level Group on disability**. This group has drawn up a list of principles to govern the quality of services for people with disabilities\(^18\), which, because they are general, can be promoted in many different countries.

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17. Also known as the PDCA cycle : Plan - Do - Check - Act, by William Deming – quoted in Joing, J.L., Auditer l’éthique et la qualité ; pour un développement durable, AFNOR, 2002
A service of quality should constantly focus on the following aspects:

- Observance of users’ rights, their choices and interests;
- A person-centred approach to the intervention;
- The continuity of care and interventions, throughout the person’s different life-cycle stages, if necessary;
- The participation of users in the planning and evaluation of the service;
- Partnership in the delivery of services;
- A service results-oriented service;
- Good governance of the service.

2. In some countries, the quality of services is linked to the more general concept of quality of life, and so to the constant improvement of disabled peoples’ living conditions:\(^{19}\): emotional well-being and social relations; belonging to the community and inclusion; material well-being, personal development and constructive activities; health; self-determination with regard to day-to-day choices and decisions and to the person’s life-project; civic rights and participation in public life; protection against violence and all other forms of abuse.

3. For the Social Platform\(^ {20}\) (an alliance of representative federations and networks of non-governmental organisations active in the social sector in Europe), the quality of social and health services is a crucial to improving access to these services for users. In September 2008, the Social Platform, which promotes the need for a general quality framework for European countries, published a paper entitled, “9 principles to achieve quality social and health services”\(^ {21}\), outlining its proposals for this joint framework:

Thus, for the Social Platform, a quality social and health service should:

- Respect human dignity and fundamental rights;
- Achieve expected results;
- Be tailored to each individual – a key factor with regard to access;
- Ensure security to all its users, including the most vulnerable;
- Be participative and be provided in partnership with the local community and other key players;
- Be provided by skilled professionals working under good employment and working conditions;
- Be accountable and managed in a transparent way.

The quality of services is therefore no longer described in terms of highly detailed “standards”, but rather in terms of “principles” applicable in all settings and which can then be declined as indicators and concrete actions by each country’s decision-makers and service providers. As a general rule, once these quality principles have been turned into concrete and verifiable actions implemented by the service providers themselves or by the authorities at various levels (for example, quality manuals or procedure manuals, however simple), we can consider that the service offers the right preconditions for quality service provision, and so for becoming responsive and accessible to its users.

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20. [http://www.socialplatform.org](http://www.socialplatform.org)

Access to services: A central theme of the Convention on the rights of persons with disabilities (CRPD)

The UN Convention on the Rights of Persons with Disabilities (UN CRPD) represents a huge step forward for the promotion of access to services for people with disabilities in all contexts and environments. It does so using a holistic and integral approach: both through articles related to different kinds of services and through cross-cutting principles, involving all relevant stakeholders. This approach paves the way not only for improved policy-making but also for relevant and more efficient projects supported by international stakeholders.

The role of international relief and development actors is fully acknowledged in this Convention, which sets out the obligations applicable to their actions. This is of particular importance in countries and contexts that can be characterized as “challenging environments”, where the roles and responsibilities of these actors can be crucial in ensuring access to services for large parts of the population.

The following six core principles explain how access to services is addressed by the CRPD.

ACCESSIBILITY IS A CROSS-CUTTING OBLIGATION, ACCESS IS A RIGHT IN ITSELF

a. Access has four dimensions:
   - **social** – eliminating social barriers such as stereotypes and prejudices;
   - **communication** – ensuring that the visually impaired, blind, hearing impaired, deaf, non-verbally impaired and other persons have access to information via an accessible means and form of communication;
   - **intellectual** – providing easy-to-read and plain text versions, particularly for persons with intellectual impairments;
   - **physical** – removing existing barriers.

There is an immediate implementation effect to accessibility: no new barriers should

Through neglect, ignorance, prejudice and false assumptions, as well as through exclusion, distinction or separation, persons with disabilities have very often been prevented from exercising their economic, social or cultural rights on an equal basis with persons without disabilities. The effects of disability-based discrimination have been particularly severe in the fields of education, employment, housing, transport, cultural life, and access to public places and services.

General Comment adopted in 1994 by the Committee that monitors and guides the implementation of the International Covenant on Economic, Social and Cultural Rights.


be created, i.e. the planning and design of new buildings and transportation, programs and other modes of implementation must be accessible to and include persons with disabilities\textsuperscript{24}.

b. Access: a principle, a process and a right
Based on the encompassing nature of “access” the CRPD makes accessibility an overarching principle, meaning a cross-cutting aspect related to the implementation of every article of the Convention\textsuperscript{25}.

**ALL SERVICES “FOR ALL” MUST BE MADE ACCESSIBLE**

- **Birth registration** (Articles 12, 18) is critical for children with disabilities, who are disproportionately affected by registration refusals, which constitutes a denial of citizenship and consequently a denial of access to basic services such as health care and education\textsuperscript{28}.

  “Without birth registration children with disabilities are not recognized in law and they become invisible in government statistics\textsuperscript{29}.”

- **Education** (Article 24)
  Persons with disabilities are to be included in the general education system, with access to free and compulsory primary education, secondary and tertiary education as well as vocational training and lifelong learning opportunities. Individual support and reasonable accommodation should be provided when necessary.

- **Health** (Article 25)
  Persons with disabilities should have access to “health services that are gender-sensitive, including health-related rehabilitation”. These have to be provided “with the same range, quality and standard of free and affordable health care as provided to others, including in the areas of sexual and reproductive health and population-based public health programs;” (a).

  Health services “needed by persons with disabilities specifically because of their disabilities” are to be provided (early identification and intervention, services designed to minimize and prevent further disabilities) (b).

\textsuperscript{24} Article 4 CRPD
\textsuperscript{25} Article 3: General Principles.
\textsuperscript{26} Ibid. p. 67
\textsuperscript{27} While Article 9 mainly focuses on the physical and communication aspects of “accessibility”, all the aspects are amply covered throughout the Convention:
- social barriers (in the preamble and in Article 1);
- communications (in Article 2 - Definitions, Article 21: Freedom of expression and opinion, and access to information, and other additions mentioning particularly sign language);
- intellectual: an additional specific mention in Article 29: Participation in political and public life.
\textsuperscript{28} Ibid. p. 62
\textsuperscript{29} CRC, General comment 9, The rights of children with disabilities, paragraph 36
Habilitation and Rehabilitation (Article 26 - 1) is seen in a broad sense, as they should “enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”. (...) “States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programs, particularly in the areas of health, employment, education and social services” (...).

Work and Employment (Article 27) for persons with disabilities is both a non-discrimination and an accessibility issue, as is Participation in cultural life, recreation, leisure and sport (Article 30). Article 27 encompasses access to “general technical and vocational guidance programs, placement services and vocational and continuing training” (d), as well as the promotion of “vocational and professional rehabilitation, job retention and return-to-work programs for persons with disabilities” (k).

Adequate standard of living and social protection (Article 28), includes measures to ensure access for persons with disabilities to (paragraph 2):
• clean water services;
• appropriate and affordable services, devices and other assistance for disability-related needs;
• social protection programs and poverty reduction programs;
• for persons with disabilities living in situations of poverty: assistance from the State with disability-related expenses, including adequate training, counseling, financial assistance and respite care;
• public housing programs;
• retirement benefits and programs.

SUPPORT SERVICES FOR PERSONS WITH DISABILITIES ARE NECESSARY

Support services play a key role in making the environment and communication accessible to persons with disabilities. They are explicitly mentioned in the Convention in relation to:

Accessibility (Article 9 - e): “Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters (...)");

Living independently and being included in the community (Article 19 - b) mentions “a range of in-home, residential and other community support services, including personal assistance” necessary to support living and inclusion in the community;

Rehabilitation (Article 26 – 3) refers to the “availability, knowledge and use of assistive devices and technologies” (...), and Personal mobility (Article 20 - b) adds reference to “quality mobility aids” and “forms of live assistance and intermediaries” (...).
PARTICIPATION OF PERSONS WITH DISABILITIES AND THEIR ORGANISATIONS IS REQUIRED AT ALL LEVELS

This is a crucial and cross-cutting point of the Convention, positioned as a General Obligation (Article 4 – 3): “In the development and implementation of legislation and policies (...) and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations.” (…)

This principle applies to the service provision process: at individual level for users; at service level for groups of users, formal or informal users’ organisations; at system and policy level for Disabled People's Organisations, parents' organizations, etc. For persons with disabilities, it may require paying attention to learning life skills, and this is also mentioned in the CRPD: “States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community". These skills include mobility skills (Article 20 - c).

Training programs regarding persons with disabilities and their rights should also be promoted.

COMPLEMENTARY TOOLS AND ELEMENTS TO ENSURE ACCESSIBLE SERVICES

► “Universal design” means the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. It should apply to services including in the development of standards and guidelines.

► “Reasonable accommodation” means making the necessary and appropriate modifications and adjustments, without imposing a disproportionate or undue burden, where needed in a particular case, to ensure persons with disabilities can enjoy and exercise their human rights and fundamental freedoms on an equal basis with others.

Significantly, the denial of reasonable accommodation is considered as discrimination.

► Positive or affirmative action through specific measures is supposed to compensate for persistent inequalities towards a disadvantaged group. Positive or affirmative action has been used as a viable means of ensuring the inclusion of persons who were previously excluded. “Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination” (…)

Affirmative action programs are mentioned in relation to the promotion of the employment of persons with disabilities in the private sector.
Community-based support
These services and facilities should be made available at community level (Article 19 - c). Community-based Services describes a comprehensive strategy, which involves persons with disabilities, and seeks to ensure that they participate equally in the different aspects of community life. Mention is also made to the need to make services available “as close as possible to the persons’ communities, including in rural areas” in relation to health (25 c) and to habilitation and rehabilitation (26 b).

Training and capacity building of professionals working with persons with disabilities
This is another general obligation (Article 4, 1 i): “To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.”

This obligation covers training and disability awareness, it is more precisely described in relation to accessibility issues (Article 9 - c), and the mobility skills of persons with disabilities and the specialist staff working with them (Article 20 - c), and also to education, health and rehabilitation where these are major preoccupations:
• Education (Article 24 – 4): “training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.” (…);
• Health (Article 25 - d): “Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care”;
• Habilitation and rehabilitation (Article 26 - 2): “(…) promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services”.

Awareness raising and promotion
More generally, the Convention:
• has a specific article on the obligation to set up awareness-raising measures (subject of article 8), (…) (a) “To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities” (…);
• mentions the implementation and the “promotion of research, development and use of universally designed goods, services, equipment and facilities, standards and guidelines, as well as new technologies” including all assistive technologies (Article 4 – 1 f, g).

HOLDING THE ACTORS OF PRIVATE SECTOR AND INTERNATIONAL COOPERATION ACCOUNTABLE

Private actors and third parties
States bear the ultimate responsibility for the promotion, the protection and the fulfillment of the rights of persons with disabilities, but this means that they have to ensure that all the actors in their territory comply with the provisions set out in the Convention.

States are far from the only duty bearers as regards access to services for persons with disabilities.

Discrimination on the basis of disability by any person, organisation or private enterprise is to be eliminated40.

40. General Obligations (article 4 – e)
In terms of awareness-raising (article 8), many actors should be involved: education system, (b) (…) all organs of the media (c) (…), and also the general public through campaigns (a).

Making the information accessible, also applies to the mass media, and providers of information through the Internet (Article 21 b, c).

The accessibility requirements in the convention apply to all service providers, public and private settings, infrastructures, transportation, facilities (housing, workplaces…) and all types of services which are open to or provided for the public (including emergency services). On a more general level, every time that health, rehabilitation, employment, professionals, cultural, sports and leisure services or programs, and employers, are mentioned this refers to both State or State-owned services, as well as private services41.

This also applies to the prevention of “all forms of exploitation, violence and abuse”, which means that “States Parties shall ensure that all facilities and programs designed to serve persons with disabilities are effectively monitored by independent authorities”42 (…).

All the programs referred to under Adequate Standard of Living and Social Protection, such as poverty reduction programs, in which international cooperation stakeholders are massively involved, also include public and privately-run and public or privately-funded services and programs.

► International cooperation

This is mentioned at the very beginning of the Convention (Preamble §1): (…) “Recognizing the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries” (…).

Article 11 Situations of Risk and Humanitarian Emergencies does not specifically refer to international cooperation but also includes it as delivered by a State-Party: “States Parties shall take (…) all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.”

Article 32 is dedicated to International Cooperation as a means for implementing the UN Convention. It is estimated that more than 80% of persons with disabilities live in low-income countries, and only some 4% are estimated to benefit from international cooperation programs43, this article therefore has particular significance in terms of the Convention’s implementation. It can make a highly significant difference in challenging environments:

“States Parties recognize the importance of international cooperation and its promotion, (…) and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organisations and civil society, in particular organisations of persons with disabilities. Such measures could include, inter alia:
(a) Ensuring that international cooperation, including international development programs, is inclusive of and accessible to persons with disabilities;
(b) Facilitating and supporting capacity-building (…);
(c) Facilitating cooperation in research and access to scientific and technical knowledge;
(d) Providing, as appropriate, technical and economic assistance (…).”

41. Articles 25, 26, 27, 30
42. Freedom from exploitation, Violence and Abuse (article 16 - 3)
43. Ibid. p159
Cooperation should not be understood as only applying in a North-South dimension, but also South-North, South-South and North-North.

Article 32 enshrines the concept of inclusive development: persons with disabilities are to be included in all phases of development programs: planning, design, implementation, evaluation, etc.\textsuperscript{44}

\section*{THE CONVENTION IN BRIEF}

\textbf{The Convention on the Rights of Persons with Disabilities} and its \textbf{Optional Protocol} were adopted on 13 December 2006 at the United Nations Headquarters in New York, and were opened for signature on 30 March 2007. It is the first comprehensive human rights treaty of the 21st century and is the first human rights convention to be open for signature by regional integration organisations\textsuperscript{45}. The Convention entered into force on 3 May 2008\textsuperscript{46}.

The Convention marks a “paradigm shift” in attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as “objects” of charity, medical treatment and social protection towards persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

The Convention is intended as a human rights instrument with an explicit, social development dimension. It reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms on an equal basis with others. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.

\textbf{Reference:} \url{http://hrbaportal.org/?page_id=3176&mod=standards}, Convention on the Rights of Persons with Disabilities and Optional Protocol

\textsuperscript{44} Ibid. p. 159
\textsuperscript{45} Such as the European Community
\textsuperscript{46} After 20 countries had ratified it. As of March 2010, 80 countries have ratified it.
WHAT IS A FRAGILE STATE?

There is currently no consensus on a list of fragile States. The concept of “fragility” remains vague and elusive and the situation in countries changes over time, most of the time in a non linear manner (Moreno Torres and Anderson, 2004). However, a number of common features have been identified. A fragile State is a State that is weakened by exogenous factors such as a natural disaster or an armed conflict and that presents signs of instability that makes long-term planning challenging. The government has limited capacities and willingness to improve the system of governance and civil society has limited power and cohesion when putting pressure on the government (OECD, 2008). As a result, the government is unable to perform its basic functions (i.e. ensure security, economic development and access to services).

Key definitions (Berry, Forder et al., 2004)

“Difficult environments are defined as those areas where the State is unwilling or unable to harness domestic and international resources for poverty reduction, including the delivery of basic services. Such areas typically have all or several of the following characteristics: weak governance, fragile political and economic institutions, conflict, poor economic management, or are suffering from the effects of a chronic humanitarian crisis such as high HIV and AIDS infection or repeated famine”.

“Service Delivery is conceptualised as the relationship between policy makers, service providers, and poor people. It encompasses services and their supporting systems that are typically regarded as a State responsibility. These include social services (primary education and basic health services), infrastructure (water and sanitation, roads and bridges) and services that promote personal security (justice, police). Pro-poor service delivery refers to interventions that maximise the access and participation of the poor by strengthening the relationships between policy makers, providers, and service users”.

Service delivery in fragile environment is characterised by a series of challenges: in difficult situations, the allocation of scarce resources by the government is often guided by principles based on clientelism rather than equity (Keefer and Khemani, 2003). For survival purposes, clientelism favours a specific group of the population that has privileged relationships with government officers (Brinkerhoff, 2007). The lines of accountability between the users, the policy makers and the providers are broken down (United Nations, 2004).

Secondly, the deterioration of infrastructures and the limited technical and managerial capacities of staff represent significant obstacles to the effective delivery of services. The financial capacities of the State are also very limited: the State is unlikely to be able to cover the recurrent costs of service facilities. In this situation, international donors and organisations may act as a substitute for the government (Berry, Forder et al., 2004).

Thirdly, the absence of national policies and a system of governance encourages staff to find alternative solutions in the private sector or through informal payments. The absence of a security and justice system facilitates the emergence of corruption amongst service providers and policy makers (Hills, 1996).

In terms of international assistance, the delivery of services is often characterised by the management of vertical programmes that create parallel health systems independent from mainstream public health services (Torres, 2004). These standalone programmes are managed by international agencies that apply their own international standards without adapting them to the local health system’s constraints and policies. Coordination between international actors and government is usually very weak considering the lack of political will to bring about change. In addition there is a risk that international assistance without general coordination becomes fragmented and out of step with government policies. One general consequence of international assistance is an erosion of government power (Batley, 2004) and a loss of credibility amongst the general public (Schuftan, et al., 2003).

In fragile States, international actors always face the same dilemma: how to cover the population’s immediate and urgent needs and build new service delivery system (Berry, Forder, et al. 2004). For example, international funding usually bypasses government structures and procedures to avoid corruption and inefficiencies.
Delivering services in fragile environments is very challenging. The role of international organisations and donors in the delivery of health and social services is decisive in the development of the future system. There is a trade-off for international organisations between by-passing the “failing” State and building the sustainability of the system (Berry, Forder et al., 2004). There are examples of good practice showing that the delivery of services can be strengthened by international organisations thereby ensuring both access to services for the populations in need and the capacity building for the authorities in managing services. The transition between humanitarian assistance and development as well as the transition from non-governmental organisation delivered services to government delivery needs to be carefully negotiated between all the actors in order to build bridges between the two management models (Carlson, de Lamalle et al., 2005). Three main strategies can be recommended (Berry, Forder et al., 2004) but will need to be adjusted to every context using innovative solutions:

- Strengthen pro-poor policy making functions;
- Build service providers capacities;
- Remove the barriers preventing poor people’s access and participation.

**REFERENCES**


Afghanistan
Part 2

CHALLENGING ENVIRONMENTS: MULTIPLE CHALLENGES, VARIED ISSUES

- The human rights of person with disabilities in emergency situations  PAGE 32
- Access to services for people with disabilities in emergency situations (conflicts, natural disasters, etc.)  PAGE 34
- Refugees or displaced persons with disabilities: Coping with additional difficulties  PAGE 39
- The situation of Palestinian refugees with disabilities in Lebanon  PAGE 41
- People with disabilities and barriers to health services in Uganda: Community action research on disability  PAGE 44
The international community has only recently begun considering the needs of person with disabilities in emergency situations. Between Kosovo, the earthquake in Asia and the tsunami, a reflection was launched into ways of overcoming obstacles to including these “invisible” citizens in our emergency response operations.

A CHANGE IN APPROACH

One way would be to change our approach to emergency response operations: from a humanitarian vision of military origin primarily concerned with keeping losses down to a minimum, we need to move forward to a human rights-based approach. Such a change would have a number of clear benefits for the thousands of people disabled as a result of natural and man-made disasters. A typical example would be in the way reception camps are designed and constructed. A seminar organised in Rome in 2000 by Iilitich, DPI-Italia and the Sapienza University of Rome’s Faculty of Engineering, discussed the fact that emergency reception camps are not adapted to the needs of wheelchair-users or people with reduced mobility, or to those with any other type of special needs (diet, health care, etc.). And yet the solution seems simple enough: the planning of these emergency camps should incorporate accessibility and equal opportunities criteria (United Nations Standard Rules, 1993), as well as units focusing on special needs in a human rights context.

The United Nations’ Convention on the Rights of Persons with Disabilities (CRPD) has helped here by introducing an international standard for disability rights, and specifically mentions situations of risk in its Article 11, and international cooperation in its article 32. Its provisions require governments to ensure “international cooperation […] is inclusive of and accessible to persons with disabilities”.

WORKING CLOSELY WITH DISABLED PERSONS ORGANISATIONS

If emergency programming is to reflect the rights and address the needs of person with disabilities, humanitarian aid organisations and disabled persons organisations (DPOs) must work together. Indeed, a society that excludes person with disabilities to the point of overlooking their human rights has only very limited knowledge of its disabled citizens, seeing them simply as dependant people who must be cared for. In reality, disability “results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others” (Preamble to CRPD). It is society’s duty to guarantee equal rights and non-discrimination for all by removing obstacles, restrictions and unequal treatment. A good example of this is the collaboration between Italian Civil Protection and the FISH (Italian Federation for Overcoming Disability) during the earthquake in Abruzzi region. During the initial emergency relief phase, there was direct contact between health services and the network of local and national associations for disabled people.
and their families. The result was a series of specific interventions and actions for people with autism, people with visual and hearing impairments and people with reduced mobility.

SETTING UP NEW FORMS OF INTERVENTION

A final consideration concerns the type of support that should be provided for people who have become disabled as a result of a natural or man-made disaster. The most effective approach is based on the empowerment of disabled people. As a result of society’s negative perceptions of disability, disabled people see themselves as incapable, of being unable to live in society and can only imagine a bleak future of dependence and limitations. To put an end to this long-standing perception of disability, emergency programmes need to include capacity-building and social inclusion services. For the many people who lost a limb in the earthquake in Haiti, for example, it could be useful to set up a system of peer counselling in which people with pre-existing disabilities provide support to those who have recently become disabled and help them to acquire the skills they need to become self-reliant and lead an independent existence. Or, again in emergency situations, personal support services could be set up in collaboration with Disabled Persons Organisations.

NEW OBLIGATIONS FOR A GREATER NUMBER OF STAKEHOLDERS

The United Nations began focusing on the issue of disability in emergencies after the tsunami. All their offices and agencies are now required to mainstream the principles and standards outlined in the CRPD. It is a new challenge, a new priority. Further good news is the General Assembly’s resolution on disability and poverty. Via the Millenium Development Goals, it has been recognised that unless disabled people are brought into the development mainstream, it will be impossible to reduce poverty. This focus on disability and poverty should have a positive impact on emergency response operations.

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Access to services for people with disabilities in emergency situations (conflicts, natural disasters, etc.)

Thomas Calvot, Technical advisor Emergency and Disability, Handicap International
(Text adapted from original text)

During the emergency phase of a crisis, the immediate impact on people with disabilities and their families is often disastrous. According to an analysis by Handicap International, they suffer from a triple disadvantage:
► They suffer the same impact of the crisis as the general population;
► They are less able to cope with the deterioration of their environment;
► The response to their specific needs (sometimes essential to their survival) is postponed or disregarded.

ALARMING FINDINGS

The need to provide diligent and, therefore, inclusive assistance to people with disabilities, during the various stages of an emergency response operation is now more widely recognised by international stakeholders and government bodies. However, despite a certainly inadequate but existing legal framework and well-structured and accepted recommendations, the level of inclusion and participation of people with disabilities during crisis situations remains highly inadequate or even non-existent. It is therefore still necessary, from the crucial moment of the initial emergency response, to propose highly direct and practical solutions.

A humanitarian crisis has a major and immediate impact on people with disabilities and their environment

A crisis increases the prevalence of impairments and disabilities among affected populations:
► An earthquake or an armed conflict causes a large number of injuries, complex fractures, spinal cord and head injuries, etc. which can lead to permanent impairments or disabilities. During the aftermath of an earthquake, we usually find that around 55% of injured persons suffer from fractured bones, 5% need an amputation and 5% have spinal cord injuries.
► The breakdown in the continuity of community health services, and the displacement and concentration of large groups of people, increases the risk of epidemics.
► In a conflict situation, the use of certain weapons (landmines, cluster-bombs, etc.) creates an additional risk of serious injuries and amputations, even after the crisis is over.

47. Thomas Calvot, Inclure les personnes en situation de handicap dans la réponse d’urgence à une crise : Réagir face aux constats alarmants du terrain, in Human Development, Disability and Social Change, Vol. 18, n°1, 2009
48. Paying insufficient attention to the needs of people in disabling situations whenever and wherever humanitarian crises occur is a denial of their rights – Speech by Jean-Baptiste Richardier at the 21st World Congress of Rehabilitation International in Quebec from 25 to 28 August 2008
The crisis affects the physical integrity of some people over the short-term:

- Poor access to the basic essentials of life, including food, water and shelter, threatens the integrity of bodily functions.
- It creates or worsens pre-existing disabilities due to a sudden inability to access essential care or appropriate treatments (e.g. insulin for diabetics, antiepileptic drugs, etc.).

A crisis has a major negative impact on the environment, which may lead to the loss of:

- **Technical aids and enabling devices** (walking aids, wheelchairs, visual aids, prostheses and orthoses), since people with disabilities often have to abandon these items when they leave an area in a hurry.
- **An enabling physical environment**, often chosen and improved by a disabled person, such as a place of residence or accessible routes in the surrounding area.

For example, during the displacement of people in the north-west of Pakistan since May 2009, which has affected almost two million people, we found that, among the people who received care from us, 47% of vulnerable people had an immediate need for a technical or mobility aid. In the Gaza Strip, following the conflict at the beginning of 2009, this need “only” concerned 27% of the operation’s vulnerable beneficiaries because the hostilities had not given rise to massive population displacement.

**However, recommendations to include people with disabilities are not put into practice by humanitarian response operators.**

Generalist emergency operators do not take the necessary steps to ensure the aid they provide is accessible and inclusive. During natural disasters, as during conflicts, case studies and reports confirm this state of affairs, as does the joint advocacy paper drawn up in 2009 for the United Nations High Commission for Refugees (UNHCR). At the same time, the specific solutions offered by specialist agencies or disabled persons’ organisations are marginalized and insufficiently supported. In short, people in disabling situations are not taken into account whenever and wherever humanitarian crisis occur and, beyond this, their equal right to assistance, which is denied on a day-to-day basis.

50. People with disabilities, the elderly, the chronically ill and injured persons
52. Some examples from other documents:
PEOPLE WITH DISABILITIES AND ACCESS TO HUMANITARIAN AID: FALSE NOTIONS

► There is a tendency to believe that people with disabilities have died during disasters or conflicts because they could not escape or find shelter.
► Emergency operators tend to think that global relief measures cover basic needs for all and that the response to the specific needs of people with disabilities can be postponed to the post-emergency period.
► Disability issues are usually thought to require highly specialised expertise, costly facilities and complex programmes.
► Lastly, generalist emergency operators do not take the necessary steps to make their relief accessible, and the specific solutions proposed by organisations specialising in disability are marginalized or postponed. People with disabilities are not taken into account in a timely and appropriate way, and thus deprived of the humanitarian aid to which they are entitled.

Sri Lanka, 2005
IMPLEMENTING MULTI-DIMENSIONAL ACTIONS
Identifying ways of responding to each consequence of a crisis:

➤ mitigating risks (primary health, epidemics, landmines and unexploded devices, etc.),
➤ meeting the basic needs of people with disabilities and their families (food, drink, shelter, ability to move around, etc.),
➤ covering their needs in terms of health care and specific treatments, emergency rehabilitation, the replacement of technical aids, and the supply of orthoses and prostheses.

The distinction between basic and specific needs becomes blurred in a crisis. For example, for someone with a recent spinal injury to have a normal mattress, an adequate supply of food and water, and the possibility of enjoying basic standards of hygiene will probably double or triple their chances of survival.

Simultaneously combining early action, an initial situation assessment, and advocacy activities targeted at other aid operators

Our experience of previous crises under similar circumstances shows that it is vital to take immediate or early action. The initial response is general in terms of the target population and simple in terms of meeting basic needs. The more detailed the situation assessment, the more specific the response becomes. Immediate action helps produce and enhance the quality of an initial assessment because victims are more likely to talk about their situation if they receive aid at the same time.

Identifying the situation facing vulnerable people and assessing their needs provides the basis for a rapid initial situation assessment. Its quality and ability to evolve are vital to ensuring a relevant and effective mid-term response. This assessment:

➤ immediately discredits “theories justifying inaction” and justifies the relevance of considering and responding to the needs of people with disabilities and, more generally, vulnerable people. It underlines the need for other operators to mainstream disability issues into their actions.

➤ serves to determine the immediate priorities of people with disabilities and identifying those requiring more specific attention.

➤ provides a means of assessing needs before and after the humanitarian crisis.

Lastly, experience shows the need to immediately advocate for the mainstreaming of disability issues by other operators, from the start of the humanitarian response. The more advocacy is delayed, the more it loses its meaning and the less the needs of people with disabilities are included in projects organised by emergency operators. For advocacy to be effective, it must remain realistic, rooted in a search for efficiency, and accompanied by highly practical advice.

53. Paying insufficient attention to the needs of people in disabling situations whenever and wherever humanitarian crises occur is a denial of their rights – Speech by Jean-Baptiste Richardier at the 21st World Congress of Rehabilitation International in Quebec from 25 to 28 August 2008
Disability and Vulnerability Focal Point (DVFP)

The DVFP is a mechanism developed by Handicap International to ensure the basic and specific needs of vulnerable and disabled persons are met with an efficient and multidimensional response. The DVFP is a temporary facility set up in an affected community to identify and assess needs, supply services and refer patients. Based on a simple structure and mobile teams, the DFVP makes it possible to assess needs on a permanent basis, wherever the DFVP is located. It is capable of providing a range of responses. These include health, protection, non-food items, but also specialist support, such as rehabilitation or other services. The DVFP also provides partners with information and raises their awareness of disability.

Together, these Disability and Vulnerability Focal Points offer a support and referral network for people with disabilities, coordinated by an operator attentive to and conversant with disability issues.

This network:
▶ Constitutes a means of identifying people with disabilities,
▶ Performs an accurate assessment of their needs,
▶ Informs them of what they have a right to and how to access it,
▶ Refers them to other more general operators (e.g. for food supplies, shelter, health care) for immediate relief,
▶ Meets their more specific needs by providing them with rehabilitation care, technical aids, mobility aids, etc.,
▶ Offers a reliable database suitable for use by other operators to build up a reliable profile of affected vulnerable populations and their needs.

Highly effective in providing direct help to the largest number of people with disabilities, a DVFP network offers other advantages:
▶ it is capable of being set up very quickly,
▶ it “empowers” victims who express their needs and request assistance to which they are entitled, beginning a transition from victim status to actors in control of their own lives,
▶ it offers a source of information and useful support for other emergency operators to learn how to best respond to the needs of people with disabilities and their families.

Lastly, the DVFP encourages victims to interact, overcome their isolation, support each other and develop resilience mechanisms.

Handicap International has already adopted this approach on numerous occasions in a wide variety of crisis situations.  

54. Text adapted from original text: Refugees/displaced persons with disabilities: perspective from the field, Emergency Response Division, Handicap International - With contributions from Annie Lafrenière and Aleema Shivji
Refugees or displaced persons with disabilities: perspective from the field

Emergency Response Division, Handicap International
(Adapted from the original version)

Persons with disabilities are confronted with the same difficulties as any displaced person, when fleeing in dangerous situations, in temporary accommodations or in situations of repatriation or resettlement. But they also have to face additional challenges, linked with likely reduced mobility, communication barriers, discriminations, separation from relatives or caretakers. Besides, they tend to be largely overlooked by humanitarian stakeholders. Yet, the World Health Organization calculates there to be between 3 and 4.3 million people with disabilities among the world’s 43.3 million refugees, displaced or stateless persons and asylum seekers.

To bring appropriate response, it is essential to understand precisely what the actual gaps and challenges are. The following information is taken from some of the lessons drawn from Handicap International’s experiences on the field on contexts of displacement in particular in Central African Republic, Sri Lanka and in the Democratic Republic of Congo.

THE MAIN DIFFICULTIES FACED BY PERSONS WITH DISABILITIES IN SITUATIONS OF DISPLACEMENT

- Heightened risks during flight from dangerous situations (risk of being left behind, need of assistive devices or physical assistance to flee),
- Loss of livelihood tools and adaptive aids during flight,
- Disruptions to social networks such as loss of caregiver or family support,
- Negative consequences on disability due to lack of access to timely regular and specialized health services,
- Barriers to accessing food / non food items / tools distributions including inaccessible distribution points, lack of special food rations, unable to stand in long line-ups, difficulties to carry the received items,
- Obstacles to accessing water and sanitation facilities such as inaccessible structures, discrimination and inability to carry standard water containers,
- Isolation due to inaccessible shelters and distant location from camp services,
- Discrimination in livelihood responses including difficulties to participate in food or cash for work schemes, training or education programs, and other employment opportunities,
- Harassment, injury or detention by security forces due to type of injury (i.e. amputation) or barriers in communication (i.e. persons with hearing / speech impairments not able to hear or respond to interrogation),

56. Refugees/displaced persons with disabilities: perspective from the field, Emergency Response Division, Handicap International (updated data for this version)
57. Including approximately 15.2 million refugees and 27.1 million internally-displaced persons (IDPs). Source: UNHCR, 2009 Global Trends, June 2010
Challenges to access documentation, tracing programs and other essential services,

Barriers to participation in response programs due to poorly collected or inexistent data on persons with disabilities,

Particular vulnerability to emotional, physical and sexual abuse (especially women and children with disabilities).
The situation for many persons living with disabilities in the Middle East is challenging, in particular when it comes to effect change in their respective countries, and especially with regard to national Governments. The problem is however compounded for the numerous persons with disabilities who live as refugees, outside of the normal protection and policy framework put into place by the government of the country in which they reside. There are a high number of refugees and internally displaced persons in the Middle East. One example though in which the challenges are keenly felt is the case of the Palestinian refugees living in Lebanon, who do not benefit from any mechanism to include them in mainstream Lebanese society and cannot therefore benefit from social policies at this level. The situation is further aggravated by the fact that Palestinian refugees in Lebanon are considered to be stateless and are therefore unable to address their demands for the respect of their basic human rights to any legal entity.

SOCIAL SERVICES IN PALESTINIAN REFUGEE CAMPS IN LEBANON

Palestinian refugees in Lebanon are highly dependent on the United Nations Relief and Works Agency (UNRWA) as a key provider of social services such as education, healthcare and social protection services. In addition to UNRWA there are a number of Palestinian as well as international non-governmental organisations who provide either temporary or permanent services for the Palestinian refugees, few of them though are active in the disability sector.

Most of UNRWA's premises are not accessible to persons with disabilities and are not adapted to provide essential services for them. The services provided by non-governmental organisations in the camps are also limited and therefore many of the demands and needs of persons with disabilities go unmet.

ACCESS TO HEALTHCARE AND REHABILITATION SERVICES

The UNRWA provides preventive and curative health care to Palestinian refugees through its health centers situated in all the camps. They can also provide secondary and tertiary hospital care through a network of contracted hospitals. Primary healthcare services cover medical care, family health planning, disease control and prevention, and health education. They are provided at no cost to refugees registered with the UNRWA. Palestinian refugees are obliged to share the cost of secondary care, tertiary care, prostheses and specialist life-saving treatment.

There is very limited access for persons with disabilities to specific health services, such as early intervention, specialist diagnoses or medical rehabilitation. Such services


are provided neither by UNRWA nor by the Palestine Red Crescent Society (PRCS) (another main healthcare provider) but have to be provided by Lebanese hospitals and clinics, often at a very high cost.

The following challenges were described by persons with disabilities and their representatives present in Lebanon:

- PRCS and UNRWA as the main medical services providers in the camps provide only short-term and acute care, with almost no provision for rehabilitation, chronic illness, disability, counseling and social support. Persons with disabilities and the sick elderly generally depend on their families who provide care and support usually involving a female member of the household;
- The provision of mental health services in UNRWA is limited. Moreover the types of mental health medication available at UNRWA dispensary are restricted;
- Several stakeholders complained that they are not properly treated in external hospitals contracted by UNRWA; moreover, people diagnosed with cancer are not fully covered, there is only partial cover for open heart surgery and no cover for cardiac catheterization or chronic renal failure requiring hemodialysis;
- PRCS hospitals still lack some of the modern equipment and therefore the persons with disabilities in need of these specialized services are obliged to go to private Lebanese hospitals and pay high additional fees which they often cannot afford;
- There are insufficient numbers of healthcare staff in UNRWA clinics. Doctors treat a large number of patients each day by limiting the time of each consultation, meaning the clinics are always congested and overcrowded;
- UNRWA clinics are not accessible to persons using wheelchairs or with reduced mobility;
- Furthermore, these medical services offer limited or no accessible means of communication for persons with sight or hearing impairments and the staff have limited training in communicating with persons with learning disabilities.

Despite these challenges, there are examples of innovative programs and initiatives being implemented among the Palestinian population in Lebanon:

- Community Based Rehabilitation (CBR) services are being implemented in three areas in the North and in and around Beirut and Tyre. They are supported by international funding;
- UNRWA is implementing a similar CBR concept and setting up some rehabilitation services in the camps;
- Rehabilitation services for physical and sensory disabilities are delivered through 17 small non-governmental organisations in the camps, and although this is far from sufficient to cover all the needs, it ensures some degree of access for persons with disabilities.

ACCESS TO EDUCATION SERVICES

Due to the limited access of Palestinian refugees to public education in Lebanon and the high cost of private secondary schooling, it is not surprising that UNRWA’s education program is the largest of the agency’s programs. Children who are registered refugees have access to free elementary and preparatory education through more than 80 schools, including a number of secondary schools, and some that offer special education for children with learning difficulties.

Most of the students find themselves unable to pursue higher education at university due to their families’ low income levels. UNRWA recently established a new program that provides scholarships to a limited number of students, but unfortunately without any
specific requirements to ensure equal access for students with disabilities. Moreover, the agency runs two vocational training centers (one in the North area and one in the South), which offer vocational and semi-professional courses. Again, neither provide inclusive or specialized courses for persons with disabilities.

The majority of UNRWA schools are rented and several of them are insalubrious and in poor condition. Furthermore, most of the schools premises are inaccessible for children with disabilities, with classrooms on the first or second floor with no elevator, inaccessible bathrooms, and no sign language interpreters or aids for students with sensorial impairments.

According to information provided by parents and children with disabilities, the UNRWA schools and education systems must change so that they become supportive educational communities where every child’s right to education is met. For this to happen, various reforms and changes must take place:

- Teachers, schools and the education system need to change in order to better accommodate the diversity of pupils’ needs and include them in all aspects of school life;
- The barriers within and around the school that hinder learning and participation, must be identified and then and reduced or removed;
- The curriculum needs to be changed and adapted. Curricula in general have not been updated for several years, and do not address the demands and rights of children with disabilities, the system is far from suitable for children with intellectual disabilities or learning problems;
- Changes in UNRWA’s educational policies and their administrative structures, in how teachers teach and how students learn, as well as changes in how students access facilities and information and how they communicate are necessary to increase the inclusion of persons with a disability;
- There are a large number of kindergartens in the camps, but most of them are not accessible for children with disabilities and sometimes they do not follow the standard curriculum for kindergartens and do not comply to safety and security standards;
- Recently two early intervention units were established in the South, one in Tyre and another one in the Saïda. Both units provide specialized rehabilitation services using the multidisciplinary approach for children with disabilities from 0 to 6 years old.
INTRODUCTION

Since 2005 a programme of Community Action Research into Disability (CARD) has been underway in Uganda. All stages of the research – including the choice of research questions - are led by teams of persons with disabilities and representatives of disability non-governmental organisations working together with researchers at the faculty of Special Educational Needs at Kyambogo University in Kampala and overseas partners. One of the first research topics identified by CARD team members was the access of persons with disabilities to health services. A qualitative study exploring the experiences of 30 persons with disabilities and 10 health workers living and working in urban and rural areas of the Mbarara District was conducted. The aim was to identify the challenges that people with visual, hearing and musculoskeletal impairments experience when accessing health services with a view to making recommendations for policy and practice. Twenty-nine interviews, four focus group discussions and twelve observations at the homes of persons with disabilities and at healthcare institutions were conducted. Photographs were also taken by the research team members of the home and health centre environments. Local government Health Centres are the first point of contact that most Ugandans (who live rurally) have with the health system. There, persons with disabilities should receive equal standards of care as able-bodied community members, including referral to higher-level specialist services. As outlined below, this was not found to be the case.

60. CARD formed out of an association between Professor Sally Hartley from the University of East Anglia, the Community Based Rehabilitation (CBR) staff of Kyambogo University in Kampala Uganda and Ka Tutandike, a non-government United Kingdom based organisation operating in Uganda and focusing on equality related activities. For more information see: http://www.katutandike.org/news.php?sid=84&ptid=12
Persons with disabilities experienced a multitude of barriers when trying to access health services, the most common of which was being unable to afford the transport costs to get to the health centres which may be up to 6 miles away from their home. Transport was reported to be more expensive for reasons related to their disability. People with hearing impairments needed to take an interpreter with them, people with physical impairments often needed a more expensive form of transport than a motorbike, and they might be charged double the fare if their wheelchair took up space in a bus. An ambulance service was provided by one rural health centre to transport children only, but was prohibitive to many families because they had to pay for the costs of fuel. “We cannot afford transporting the children to Mbarara Hospital every time they are sick because it is too expensive. That girl needs a car because she cannot sit upright on the motorcycle or in taxi, and the boy is very lame.” (Visually impaired man).

Persons with disabilities reaching the Health Centres reported many difficulties in actually accessing services as a result of inaccessible infrastructure and negative behaviours by staff. In one case, a man who had crawled on the ground to get to the hospital was turned away by staff because he was dirty. Others had to leave their wheelchairs outside the hospital and crawl inside on the dirty floor because there was no accessible ramp. Persons with disabilities often struggled with long queues and the lack of sign posts, and wished for a service or help desk to be made available specifically to them. An individual health worker reported prioritising persons with disabilities in queues, and another said that she would transfer mattresses from the beds to the floor, but these were individual decisions and were not based on formal policies or guidelines. “The medical staffs do not care. One day a crawling disabled man came to the hospital when he is dirty because of crawling on the road but all the medical staff did not want to attend to him.” (Physically impaired woman).

A particular challenge for people with hearing impairments was communicating with health personnel. Health workers did not understand sign language and this was a concern in terms of making an accurate diagnosis and prescribing the right treatment. Family members acting as interpreters were felt to invade the privacy of persons with disabilities, but training health workers in sign language was not a simple solution. One hearing-impaired respondent had trained twelve nurses in some basic sign language but warned that this even this was of limited use due to use of locally-specific sign languages. “The biggest problem is the lack of history of the disease because of lack of expression of the deaf patients.” (Health worker).

Both persons with disabilities and health workers reported problems with the availability of treatments. One health worker reported “The medicine is not enough and some are never in stock so we prescribe it for the patients to buy it from elsewhere.” Persons with disabilities in urban areas were better able to cope with the lack of reliable supplies at government health centres, as they were more likely to have jobs that provided them with the cash necessary to go to private clinics. Those in rural areas had to create work for themselves that would generate cash.

Problems were also perceived with provision of assistive devices even in urban areas. One physically impaired female explained: “There are no shoes and crutches for us. Sometimes government sends shoes but getting them is difficult because you have to keep going there but they don’t give you. By the time they decide to give them to you, your size is not there. At least if they could measure our feet and know the real size of my feet then bring them.” (Physically impaired woman in urban area).
CONSEQUENCES
As a result of the difficulties experienced in accessing health services, persons with disabilities in rural areas tended to go to health centres as a last resort or not at all. Some would use locally available alternatives, such as herbs. Some used able-bodied family members to represent them at hospitals, but treating persons with disabilities \textit{in absentia} was perceived as a real concern from health workers’ point of view. Pregnant mothers delayed accessing antenatal clinics to the point where they and their unborn child were at significant risk: “They fail to attend antenatal clinics and so fail to know when they are due. So they come when it is overdue and sometimes we are forced to refer them to Mbarara Hospital because of complications which cannot be handled here.” (Midwife in rural health centre).

RECOMMENDATIONS
At the moment, national\textsuperscript{61} and international\textsuperscript{62} legislation on the rights of persons with disabilities to respect, dignity, and opportunities to realize their full potential, are not enforced in the Ugandan health systems. Changes in health care policies and practices are urgently needed in order to equalize health opportunities between people with and without disabilities in Uganda. Priorities amongst these include:

\begin{itemize}
\item Training the existing community based services to increase levels of awareness of health care providers and persons with disabilities about important issues relating to persons with disabilities’ access to health care,
\item National Union of Disabled Persons of Uganda to consider raising the awareness of Local Council disabled representatives about their potential role in improving access for persons with disabilities to local health care,
\item Providing sign language training for community based workers and link them to health service centres to translate and improve understanding between service providers and service users.
\end{itemize}

ACKNOWLEDGEMENTS
Thanks to all people who participated in this study and to Ka Tutandike for funding.

\textsuperscript{62} UN Convention of the Rights of Persons with Disabilities (2007): \url{http://www.un.org/disabilities/convention/about.shtml}
Uganda ratified the Convention and the optional protocol on September 25th, 2008 (editor’s note).
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Point of view: Towards free social services?

Charlotte Axelsson and Darryl Barrett.
(Text adapted from original text)

The present article refers to all the measures required to allow everyone, including marginalised and socially excluded populations, financial access to social services at community level.

A service could be considered affordable if it...

► Is free of charge or has a nominal fee based on a means test for all users with a sliding scale to ensure realistic payment division;
► Develops mechanisms to ensure long-term funding;
► Knows the costs of transportation, meals or accommodation, and for accompanying family members and takes these into account in the overall service provision.

Stakeholders indicated that despite governments in the region stating that many services (e.g. health and education) are free, sometimes persons with disabilities are required to pay additional fees for the services, medication or assistive devices they require due to their disability. Private services providers who may provide higher quality services than the free or low cost public services are also reportedly charging fees that are unaffordable for persons with disabilities.

Stakeholders noted that basing the assessment and identification of disability on impairment alone is not the best method. To address this issue, some private and public services assess the social situation of a person with a disability to determine if they would benefit from free or low cost assistance, based on their income and overall economic status. Whilst this system of means testing or “social study” exists, it needs to be developed further to ensure a more appropriate use of resources and a better allocation of funding. Some stakeholders recognised however, that this system would continue to be hampered as long as the medical model for disability remains prevalent when categorising disabilities.

HEALTH AND HEALTH-RELATED REHABILITATION SERVICES

There is legislation in place in Middle Eastern countries. Health services for persons with disabilities and their families are free, as they are covered by government provided health insurance. The reality however is that this is not always the case. Persons with disabilities in the occupied Palestinian territories for example, can access public health services when their “disability percentage” exceeds 60%. This figure is criticised partly because...

it is based on an old Jordanian law from 1951 and also because a new Palestinian law changing this has not been implemented due to financial constraints. Many countries in the region do offer free or low cost services (e.g. primary health, basic hospitalisation and education), supported by different government initiatives. For example, the Disability Fund in Yemen provides funding to support health services for persons with disabilities, although the implementation in rural areas is severely limited and there is an issue regarding the quality of some of the health services provided. Persons with disabilities in Lebanon also are entitled to full health cover, with assistance from the Rights and Access Programme and on the condition that they hold a disability card issued by this programme. In Egypt, since 1998, all children, including children with disabilities are provided with universal health care. In general though, the need for improved health insurance systems is strongly felt, as the systems currently in place in some countries have been shown to be unable to meet the demands of service users. Without free or subsidised health services, as well as a geographically-balanced distribution (rural-urban), persons with disabilities will continue to struggle or be unable to access the healthcare they require. In the occupied Palestinian territories, it was estimated that only 55% of people had some form of health insurance and considering that persons with disabilities often have limited social protection or have difficulties obtaining employment, the percentage of persons with disabilities without insurance or the ability to pay for health services is likely to be higher. With respect to education, there are different specialised educational services that have arrangements with the various ministries to ensure some subsidies for the children with disabilities attending these special schools. For example, some specialised education settings receive a small daily allowance from the government for each child with a disability receiving education services. Many educational facilities are free or have very low fees, but as previously noted, the extra costs associated with transport, assistive devices or educational materials often significantly increase the financial burden for the families of children with disabilities.

**FINANCIAL ASSISTANCE AND EXEMPTIONS**

Laws related to tax and financial exemptions for persons with disabilities are again based on a charity approach. Financial exemptions in the Middle East can be seen in the areas of free public transport, reduced or fully covered travel costs for accompanying carers and customs exemptions on new vehicles. Debate amongst disability stakeholders on this issue is evident, with some stakeholders believing that exemptions should be improved and increased, particularly those for transport and accessibility whilst others believe that exemptions should be more closely linked to income and activity. It has been argued that if a person has the means to pay then an exemption should not be given as the norm, and that exemptions must apply only if required. Cash transfer mechanisms as a form of social protection and to assist with affordability of services are reportedly quite limited in the Middle East and not adequately supported by legal or policy frameworks. There are some specific forms of financial support but cash transfer systems are generally deficient. In Yemen for example, families receive cash benefits that do not exceed over 48,000 riyals, ($250 per year) in social assistance, with campaigners arguing that this does not meet basic needs and does not take into account the additional costs associated with living with a disability.  

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65. World Bank, 2007, p. 82.  
Exempting the worst-off from user fees: Action research in Burkina Faso

Ridde V.\(^{68}\), Yaogo M.\(^{69}\), Ouedraogo M.\(^{70}\), Kafando Y.\(^{71}\)
(Text adapted from original text\(^{72}\))

BACKGROUND

The recent WHO Commission on Social Determinants of Health reaffirms the need for solutions to improve the equality of access to care. In West Africa, user fees have been implemented using a community-based, decentralized approach in accordance with the principles of the 1987 Bamako Initiative (BI). To contend with the risk of exclusion created by user fees, those implementing the BI were asked to respect principle #7, i.e. to set up exemption schemes to help those unable to pay. However, twenty years later, it is obvious that in Burkina Faso (Ridde V., Social Science and Medicine, 2008), as elsewhere in Africa (Gilson L, Kalyalya D, Kuchler F, et al., 2000) this type of system has never been put in place. The most commonly cited reason for this is the difficulty in identifying who should be exempted.

INTERVENTION

This action research was carried out in 10 of the district's 25 primary health centers. The action consisted in asking the communities to select the indigents who could receive total exemption from payment, funded by BI profits. The content of the action was defined and the 10 primary health centers were chosen by the research and district teams based on three criteria: ethics (to avoid inflicting financial risk during the pilot project); sustainability (using endogenous funds); and suitability (functional management committees, participative action, adapted to the context). Consensus was reached on a definition of the indigents to be selected as: “someone who is extremely disadvantaged socially and economically, unable to look after him/herself and without internal or external resources.”

METHODS

The objective of this article is to describe and analyze the intervention implementation process. Through this analysis, we were able to identify the intervention’s key characteristics. Financial capacity was calculated using a method previously used by researchers in the same country (Ridde V., 2003; Galland B, Fontaine D, Rasidy K., 1997). A qualitative study was undertaken to analyze the stakeholders’ perception of the process by means of five Focus Group Discussions (FGD).

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71. Research Centre of the University of Montreal Hospital Centre (CRCHUM), Canada - Société d’Étude et de Recherche en Santé Publique (SERSAP), Burkina Faso
72. This paper is an adapted and shortened version of: Ridde, V. et al. (2010). A community-based targeting approach to exempt the worst-off from user fees in Burkina Faso. Journal of Epidemiology and Community Health, 64, 10-15. This action research was made possible through funding from the International Development Research Centre (IDRC) in Canada.
To our knowledge, this is the first study on community-based exemption schemes in the context of the BI in Africa. The study provides us with good and bad news. The good news is that implementing principle #7 of the BI is feasible (as a process) as is adapting it to the context. The selection of individuals perceived as indigent by the community using a community-based process was not very costly and was appreciated by the stakeholders.

The bad news is the severity of the communities’ final selection - only 3/1,000, or 6/1,000 if we retain the numbers selected by the VCs. In Mauritania, a nearly identical process produce the same results, with less than 1% of the population being identified as indigents (Criel B, Bâ AS, Kane F, et al., 2010). But in Cambodia, in a very different context, a community-based targeting approach retained 16% of the population for exemption, knowing that the funding was from external sources (Noirhomme M, Meessen B, Griffiths F, et al., 2007). In the same region, it appears that pre-identification by the community would be more effective for selecting the worst-off (very poor) as opposed to the poor (Ir P, Decoster K, Hardeman W, et al., 2008). In Burkina, this restrictive selection can be attributed to social and technical reasons. Socially, because their vision of social justice (equality) is more egalitarian than Rawlsian (and its “maximin” principle: the maximum for those who have the minimum), people are more likely to seek social peace and consensus (Ridde V., BMC Health Serv Res, 2008). Indigents were selected on the basis of a double burden, economic (lack of financial means) and social (lack of support) because the situation is that of a country ranked next-to-last in the Human Development Index. In a context of widespread poverty, it is extreme poverty that makes the difference for the population. The region’s social organisation is very hierarchical and to be labeled “indigent” can sometimes “dishonor the family”, we were told. This social hypothesis had been advanced in a study of three pilot projects in Africa (Noirhomme M, Thomé J-M., 2006). Technically, the (equitable) use of the endogenous resources generated by BI user fees was not widely promoted and this therefore hindered the selection of indigents. The MCs had a conflict of interest, as no third-party purchaser was involved.

**RESULTS**

**Selection of indigents**

The 124 Village committees (VCs) selected 566 persons. The 10 management committees (MCs) retained 269 persons (48%), i.e., 2.81 per 1,000 inhabitants. Less than 5% of the VCs selected more than 10 persons, and 15% of them did not select any. Half the indigents were women (134/269) and 63% of the indigents were more than 50 years old. The proportion of people with disabilities amongst indigents was 62%.

**Stakeholder perceptions**

The action was well received by the stakeholders. They considered that it was beneficial for the worst-off, according to their own criteria. It was a useful tool for making the MCs’ legal responsibility towards the indigent a concrete reality. One criterion for the effectiveness of this action was the fact that it was community-based and participative, because, as one VC member remarked, “there have been other interventions that helped the indigent, but their approach was not like this one, which is much more community-centered.” It was also accepted because it respected the social context by requiring that the lists were validated and by choosing people who were very involved in the community as VC members. In the VCs, the selection process was consensual. However, the fact that the MCs only retained half of the indigents is explained by the members of MC as being due to their fear of using up the accumulated funds, and the fact that they are not fully aware of their financial situation. Some MCs expressed a lack of confidence in the selection made by the VCs and felt they were not rigorous enough in their selection.

**DISCUSSION**

To our knowledge, this is the first study on community-based exemption schemes in the context of the BI in Africa. The study provides us with good and bad news. The good news is that implementing principle #7 of the BI is feasible (as a process) as is adapting it to the context. The selection of individuals perceived as indigent by the community using a community-based process was not very costly and was appreciated by the stakeholders.

The bad news is the severity of the communities’ final selection - only 3/1,000, or 6/1,000 if we retain the numbers selected by the VCs. In Mauritania, a nearly identical process produce the same results, with less than 1% of the population being identified as indigents (Criel B, Bâ AS, Kane F, et al., 2010). But in Cambodia, in a very different context, a community-based targeting approach retained 16% of the population for exemption, knowing that the funding was from external sources (Noirhomme M, Meessen B, Griffiths F, et al., 2007). In the same region, it appears that pre-identification by the community would be more effective for selecting the worst-off (very poor) as opposed to the poor (Ir P, Decoster K, Hardeman W, et al., 2008). In Burkina, this restrictive selection can be attributed to social and technical reasons. Socially, because their vision of social justice (equality) is more egalitarian than Rawlsian (and its “maximin” principle: the maximum for those who have the minimum), people are more likely to seek social peace and consensus (Ridde V., BMC Health Serv Res, 2008). Indigents were selected on the basis of a double burden, economic (lack of financial means) and social (lack of support) because the situation is that of a country ranked next-to-last in the Human Development Index. In a context of widespread poverty, it is extreme poverty that makes the difference for the population. The region’s social organisation is very hierarchical and to be labeled “indigent” can sometimes “dishonor the family”, we were told. This social hypothesis had been advanced in a study of three pilot projects in Africa (Noirhomme M, Thomé J-M., 2006). Technically, the (equitable) use of the endogenous resources generated by BI user fees was not widely promoted and this therefore hindered the selection of indigents. The MCs had a conflict of interest, as no third-party purchaser was involved.
CONCLUSION
This experience teaches us that in the African context of the BI, decision-makers who want to increase service utilization among the worst-off should definitely consider two possible solutions. Firstly, whilst endogenous resources may be limited, they do exist (thanks to the cost-recovery schemes) and communities can select individuals whom they consider as indigent. Also, the State could legally require (and even enforce, by means of accompanying measures) that a minimum number of indigents is selected on the basis of a percentage of annual profits. Our research showed, in fact, that the health centers had the capacity to take on six times more indigent persons than the number selected by the committees. Exclusion error could be reduced by increasing the number of beneficiaries. Secondly, a community-based targeting approach should be tested with support for the worst-off funded by a third-party purchaser such as the Health Equity Funds. Further studies need to be undertaken, particularly in Africa, to evaluate the effectiveness of such mechanisms in selecting the worst-off and improving their access to care.
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Part 3.1

How to improve access to rehabilitation services for poor persons in Africa?

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(adapted from the original version?)

SUMMARY
An evaluation showed how three rehabilitation funds set up in Mali, Rwanda and Togo, have helped poor people in three countries of Africa to have a better access to rehabilitation services. The process of implementation, the impact on beneficiaries, a costs analysis and recommendations are shared to improve the sustainability.

INTRODUCTION
Persons with disabilities living in West and Central Africa countries are the poorer among the Poor. Most of them have no incomes, no insurance and nobody to support them. Moreover most of them need rehabilitation services especially prosthetic and orthotics, wheelchairs or hand-moved tricycles and physiotherapy. These services are with an admission charge and too expensive for them.

Handicap International has been working in Mali, Rwanda and Togo for years in the field of rehabilitation with governments, private partners, professionals, persons with disabilities and their associations. In order to better meet the needs of persons with disabilities three rehabilitation projects carried out by Handicap International which already support the rehabilitation centres by trainings of professionals has set up three rehabilitation funds. It’s probably the first time around the world that the model of Health Equity Funds already known for the health care is used for persons with disabilities.

These funds are based on the principle of the third-party payer; access to care is financed neither by the patients, nor by the institutions that provide the care, but rather by a third party. That third party enters into contracts with health facilities for them to deliver quality care at a given rate. In other words, the health facility plays the role of a service provider.

The management of an HEF can be entrusted either to the third-party payer or to another institution to which the third-party payer delegates this role. Managing an HEF consists in:
- Identifying and monitoring beneficiaries,
- Monitoring the quality and cost of the care provided,
- Making all necessary disbursements.

It is essential to dissociate the role of manager from the role of service provider; otherwise the third-payer principle would be undermined. In other words, the management of an HEF should certainly not be entrusted to the health facilities, because they would then de facto have funds to provide the care independently. It would almost be like giving them carte blanche and they would decide everything: care cost, quality, and beneficiaries.

METHOD
This qualitative and economic evaluation has been conducted in three Africa countries, Mali, Rwanda and Togo in 2008 and 2009. The evaluator was an external consultant specialized in economics and developing countries. During one week in each country he met more than 70 people involved in the funds as beneficiaries, associations, government, rehabilitation professionals and Handicap International’s teams. He also received all the documents and figures linked with these three funds.

OUTCOMES
1718 persons with disabilities have profited by the three funds. Females represent 60% in Mali, 54% in Rwanda and 45% in Togo. The average age was between 28 and 29. Each Fund was able to take in charge between 125 and 300 persons per year.
The three funds were set up by three independent teams without connections between the three countries. They have got different stakeholders and functioning. These three different processes have particularly an impact on their sustainability. The most sustainable fund is the one which trained and involved his partners right from the start. The average total amount of rehabilitation fees per beneficiary is about the same from one country to the others (between 140 and 193 euros). But the cost of management (setting up and managing the fund) differ from one fund to another (87 euros in Rwanda, 197 euros in Togo and 237 euros in Mali). Comparing rehabilitation fees and managements costs shows the efficiency of each fund. In Mali, 1.22 euros have to be spent in parallel for the fund to use 1 euro in FR, while in Togo 1.02 euros is enough. But it is in Rwanda that financial efficiency is the highest: for 1 euro spent, only 0.62 euro has to be disbursed in parallel. In other words, a larger part of the entire budget that Handicap International allocates to funds directly benefits Persons with Disabilities under the Rwandan fund.

RECOMMENDATIONS
What not to do in order to make an HEF successful:
► Entrust the management of an HEF to a service provider,
► Use selection procedures that are too complicated,
► Fund micro credits or Income Generating Activities using an HEF,
► Determine contributions on the basis of the total cost of the care,
► Not apply the same rules to all.

What to do to contribute to the success of an HEF:
► Entrust the management of the HEF to national institutions right from the beginning,
► Entrust the management of the HEF to a national institution established locally,
► Target beneficiaries through an effective identification system,
► Systematize the payment of a contribution,
► Reduce the dropout rate for device use,
► Reduce the time between patient identification and device delivery,
► Better take into account patients who need physical therapy only,
► Better take into account the specific case of growing children,
► Increase the operation period of the HEF,
► Conduct rigorous surveys with beneficiaries,
► Promote the creation of an association of beneficiaries for each HEF,
This study has enabled us to identify the strength and the weaknesses of the equity funds. The implementation and functioning costs are considerable. But, and it's the most important, these funds have really allowed access to poor and remote people to rehabilitation services they couldn't afford before. These funds establish an equitable, reliable system and give confidence to the donors to finance rehabilitation care which is not dealt with by the insurances. Rehabilitation care could actually change the daily life of persons with disabilities. They have right to rehabilitation services as said in the UN convention, art.26. Rehabilitation Funds are one of the best ways we can propose to improve access for poor people to rehabilitation services in developing countries.

CONCLUSION

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REFERENCES


Point of view: The need for more data in the disability field

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Disability-related statistics, as well as an integrated information system at national level (including aggregated data about disability-related aspects in the regular statistic tools) represent key elements for elaborating effective and evidence-based policies in the field of social services.

In various domains of the services reform (education, health and social care, employment, support and rehabilitation services, etc.), States should rely on accurate data in order to prioritize the necessary plans for improvement and change, as well as to invest in the development of appropriate services and social protection measures.

In the decentralisation processes that are progressively taking place in the Balkans region, a redirection of resources from national to local levels and to priority fields of intervention, require precise information about the number and the living conditions of people with disabilities in their communities, as well as to what extent their rights have been realised. Research and statistics are imperative tools for policy makers in this transition period and the recent UN Convention on the Rights of Persons with disabilities highlights the importance of this: Article 31 of the UN Convention says: “States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.”

Complementarily, the participatory disability assessments, which are not precise surveys, but can still provide good information for defining needs of services, are also very useful. These assessments are usually part of local action planning process and can easily compensate for the lack of data at national levels, in transition periods. These various types of data collection facilitate the complementarities between micro and macro planning, which is important in the early stages of decentralisation of social services. However, such overall and comprehensive information system, that could provide accurate data for gate-keepers as well as for legislators and decision bodies at local level, does not yet exist in every country.

The questions about the number and situation of people with disabilities are not yet mainstreamed in the national censuses. Very few national surveys are carried out in the region in the social field and when they exist, they are mainly the initiative of international donors (especially World Bank and other UN agencies) and they do not include extensive data on disability. The main source of data remains the registration of people with disabilities in various gate-keeping agencies, in relation with their entitlements (cash benefits, services, in kind support), in accordance with the national regulations. These agencies (commissions of evaluation and orientation in education, employment

bureaus, disability pension funds, Centres for Social Work, the social departments in the local municipalities, etc.) are not coordinated one with another and therefore the overall data is often duplicated or missing.

The data collected by these agencies is also strictly related with the definition of disability. In the countries in which a comprehensive law on protecting and promoting the rights of people with disabilities does not exist yet, each specific law (in the fields of education, health, employment, social protection, etc.) defines disability in its own way. The risk of having inaccurate statistical data in these countries is therefore much higher. While lacking precise data about persons with disability at national level, several countries of the region estimate their number at around 10% of the overall population, following the methodology of the World Health Organization.

However, when comparing these estimations with the percentages of other countries of the region (where data are collected according to existing registrations and entitlements), the results are very different. In these last cases, the percentages vary between 2-4% of the general population, as mentioned above. In addition, many children and adults with disabilities, in need for assistance, fall “through the net” of social protection entitlements, simply because they do not register as persons with disabilities or do not obtain a disability certificate. Some of these persons might not want to be considered disabled. More often, these people are simply not informed about their rights and entitlements or about the relevant agencies that they have to approach.

The lack of information regarding disability is sometimes compensated by some databases established by local non-governmental organisations (either umbrella organisations for disability issues, resource centres for non-governmental organisations, or cross disability organisations which initiate national surveys in this sector). Due to limited capacities for research and data collections, the reference groups in these cases are not very extensive. The main concern related to the databases established by non-governmental organisations remains the accuracy of data and the guarantee of confidentiality for people with disability participating in these surveys, in the context in which this type of data collection is not yet regulated by the States.
For most countries, contextualized information and research on the rights and needs of people with disabilities is often largely absent. This is particularly the case in challenging environments, typically low-income countries characterized by a fragmented institutional and organisational landscape, with fragile State structures and limited civil society movements. In these contexts (often post-conflict or complex emergency situations) policies to promote disability rights and inclusive services are usually very weak or simply non-existent. Private and international organisations too often fill the service provision void. While policy-makers and service providers in challenging environments may acknowledge the rights of people with disabilities, they often do not have the required knowledge, expertise or tools to develop accessible, inclusive services. However, that is not to say that such knowledge and expertise does not exist. Even in the most challenging environments, where resources are limited, it is possible to identify sources of considerable expertise and evidence of effective, inclusive practices.

The key issue is **how** to identify and utilize examples of good practice, with a view to replication and scaling up. In most developing countries there are few mechanisms for the analysis and exchange of good practices on access to services; for multi-stakeholder consultations on services; for exchanges between service providers; or for users (particularly people with disabilities) to influence service development.

Launched in 2008, *Making it Work* is a global initiative which aims to address some of these issues.
Making it Work (MIW) is concerned with using evidence of good practice to bridge the huge gap that exists between the international standards set by the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the actual standards of existing services, systems and policies in low income countries. This approach is now being used by projects in different regions of the world (www.makingitwork-crpd.org).

MIW can be seen as a concrete methodology for replicating and scaling up good practice. It promotes a bottom-up approach to inclusive development, where civil society actors and agencies working at the field level (particularly in countries where there are limited resources) have the opportunity to influence local and national development frameworks. The MIW approach focuses on civil society groups (including Disabled People’s Organisations), documenting evidence of inclusive practices, services or policies (i.e. evidence of what is already working well) and using this to communicate constructive recommendations to decision-makers.

Regardless of the scale or context, all MIW projects share four broad components:

1. **A multi-stakeholder approach**: civil society organisations at different levels (including Disabled Persons Organisations, service providers, international non-governmental organisations) working together to implement the project.

2. **Documenting examples of good practice**: select a key disability issue (for example access to rehabilitation services) and research practices that uphold the principles of the CRPD and impact positively on the lives of people with disabilities. The focus could be on different kinds of practices, for example the practices of local community organisations, service providers, policymakers or organisations from the private sector.

3. **Make a report: with concrete recommendations** for improving policies, services or practices (depending on the topic and scale of the project, these might target local or national policymakers; service providers; mainstream development actors; Disabled People’s Organisations; or international agencies).

4. **Use and disseminate the report**: carry out advocacy and training activities based on the report recommendations.

On the subject of access to services, the Making it Work approach could help (at all levels) to:

- Bring together the key people with a stake in a particular service – to engage in constructive dialogue and consultation (even in the absence of effective and capable policy-makers).
- Identify and agree on common standards for services that are both suited to the context and realistic in terms of the resources available.
- Capitalize on the knowledge and expertise of both specialist practitioners and service users.
- Empower users to influence the quality of their service.
- Investigate existing examples of inclusive services, from the perspectives of different stakeholders.
- Encourage cross-fertilization (at local, national, regional or international levels), exchanges across the different sectors of health, education, social and financial. The MIW approach is particularly conducive to South-South exchanges.
- Provide policy-makers and service providers with concrete and practical recommendations on how to meet the needs of people with disabilities within their communities in a way that respects their obligations under the CRPD.
The **Disability Monitor Initiative (DMI)** in both South East Europe and the Middle East provides examples of the *Making it Work* approach in action.

Originally a Handicap International initiative from 2004, the DMI in **South East Europe (DMI-SEE)** is now led by a Serbian non-governmental organisation, *the Centre for Society Orientation (www.cod.rs)*. The DMI-SEE aims to strengthen a regional movement towards the full participation of persons with disabilities in society. The initiative is primarily based on field research, consulting with persons with disabilities, service providers, civil society organisations, government officials and local authorities. Using this multi-stakeholder approach, the DMI-SEE has produced a range of publications to examine the critical issues affecting persons with disabilities in the region. More specifically, these publications have used case studies of existing good practice to make concrete recommendations for social innovation and policy reform in South East Europe. Among those publications, two focus more specifically on Access to Services, an annual full regional report\(^{75}\) and a working paper\(^{76}\), both by Diana Chiriacescu.

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The Disability Monitor Initiative in the Middle East (DMI-ME) also follows the Making it Work approach. Handicap International and CBM (Christian Blind Mission) jointly initiated the Disability Monitor Initiative Middle East in 2008. CBM as core member of the DMI provides financial, technical and Human resources including coordination. The DMI-ME has a Regional Steering Committee comprising CBM, Handicap International, Bethlehem Arab Society for Rehabilitation, Arab Organisation of Disabled People, Lebanese Physically Handicapped Union and The Al-Hussein Society for the Habilitation/Rehabilitation of the Physically Challenged.

The initiative in its first phase focused on the theme of Access to Social Services, with the following results achieved to date:

- Developing an assessment tool for analysing good practice in service provision, based on the principles of the CRPD.
- Regional research undertaken on access to social services in the Middle East.
- Publication of a range of thematic DMI-ME journals, on the UNCRPD, Access to Social Services and Education. Publication of the DMI-ME Access to Social Services for Persons with Disabilities in the Middle East, Multi-stakeholder reflections for policy reform77 and a Legislative Review: Legal Texts on Disability, Between Enforcement and Effectiveness (a regional study which aims at analyzing the lack of enforcement regarding disability laws in the Middle-East).
- Launch of DMI-ME website to exchange and disseminate information from the initiative.

In 2010, the DMI-ME report on Access to Services, together with the legal review, will form the basis of a toolkit for disability associations in the region, to support effective advocacy on inclusive policies and practices for social services.

77. Axelsson Charlotte and Barrett Darryl, Access to Social Services for Persons with Disabilities in the Middle East – Multi-stakeholder reflections for policy reform, Disability Monitor Initiative-Middle East, CBM et Handicap International, 2009. The DMI Report was developed by CBM and Handicap International. CBM is an international Christian disability & development organisation committed to improving the quality of life of persons with disabilities in the poorest parts of the world.
Using a systematic key informant method to identify children with disabilities and improve access to services: An example from rural Bangladesh

Bangladesh is prone to frequent cyclones and floods and is listed as one of the poorest nations, ranked 146 out of 182 on the Human Development Index with an exceptionally high child and maternal mortality rate. In the recent past, it has also been subject to political upheavals, military coups and states of emergency. Despite these dramatic and devastating priorities, the country maintains a strong commitment to improving access to services for its poorest groups, among which are children with disabilities and their families in the rural and remoter areas of Bangladesh.

A first challenge is always finding the most effective way of identifying these children without incurring the high costs of a household survey, or raising expectations that cannot be met. A low cost method of identifying childhood blindness using Key Informant Methodology (KIM) was proved to be successful in Bangladesh and was routinely followed by surgery, assistive devices or community-based rehabilitation interventions. It has also been used in other countries such as Malawi, and for epilepsy in India.

The effectiveness of this KIM approach is now being tested for a wider range of other conditions; visual, hearing, physical and epilepsy using the same basic model but adapted for different impairments. This systematic method involves holding training workshops in local sub districts for volunteer key informants (KIs) from the community (such as teachers, disabled people groups, non-governmental organisations or health workers, imams, local government or business people etc). A standard programme of presentations, discussion, role play with the use of illustrated flip charts and information leaflets, was adopted for each of five sub-districts, training approximately 100 key informants in each one.

These people then have 4-6 weeks to spread the key messages used to identify children and collect a list of their contact details. The assigned project Community Mobiliser (CM) coordinates the action to bring them to a temporary assessment camp setting in a local village, where a team of specialists examine, diagnose, advise, give information, counsel or make referrals.

A pilot phase was completed in 2009 in the flood prone district of Sirajganj and the results look promising. The KIM methodology proved effective in bringing large numbers of children...
with different impairments to the camps with referrals made for 88%. We had originally tested KIM with a single impairment approach in four sub districts but used a “combined” tool for the 5th one (visual + hearing + physical + epilepsy). However, the latter proved to be the most successful as more children were identified in the combined group sub district (702) than the sum of the others (570) - see table below.

The left side “Sub District” column shows the target impairment group for KIs to identify in that particular sub district and the impairment columns list number of children diagnosed with that type of impairment. However in reading across the row it shows that children may have additional impairments to the target one. There were actually 972 children who had 1,232 impairments ranging from 768 children with 1 impairment to 9 children who were diagnosed with having all four impairment types.

<table>
<thead>
<tr>
<th>Sub district type of group</th>
<th>Physical impairments</th>
<th>Epilepsy</th>
<th>Visual impairments</th>
<th>Hearing impairments</th>
<th>Disabling impairments</th>
<th>Children examined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tarash (visual)</td>
<td>9</td>
<td>2</td>
<td>22</td>
<td>4</td>
<td>25</td>
<td>40</td>
</tr>
<tr>
<td>Kazipur (hearing)</td>
<td>12</td>
<td>2</td>
<td>5</td>
<td>84</td>
<td>84</td>
<td>159</td>
</tr>
<tr>
<td>Shahjadpur (epilepsy)</td>
<td>21</td>
<td>46</td>
<td>6</td>
<td>2</td>
<td>55</td>
<td>59</td>
</tr>
<tr>
<td>Ullapara (physical)</td>
<td>244</td>
<td>32</td>
<td>16</td>
<td>35</td>
<td>263</td>
<td>312</td>
</tr>
<tr>
<td>Khamarkand (combined)</td>
<td>348</td>
<td>74</td>
<td>66</td>
<td>202</td>
<td>545</td>
<td>702</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>634</strong></td>
<td><strong>156</strong></td>
<td><strong>115</strong></td>
<td><strong>327</strong></td>
<td><strong>972</strong></td>
<td><strong>1,272</strong></td>
</tr>
</tbody>
</table>

(Pop = 100,000 per sub district)

*Subjects may have ≥ condition so that 972 children who had a confirmed diagnosis of disabling impairment had 1232 impairments out of 1,272 examined*
In addition KIs were more active in identifying children and the CMs felt more comfortable when they could help a majority of children with disabilities in a village.

Where possible service provision is made through established or activated systems locally, or where necessary to further districts where more specialised treatment is available. In the pilot study for example, there was an eye hospital located in one of the sub districts which offered free cataract surgery, a local Maternal and Child Health (MCH) facility was approached to follow up children with epilepsy medication for a small administration fee, a newly established otolaryngology department in another local sub district was prepared to accept routine ear problems, whilst more complex cases were referred to a specialist non-governmental organisation centre in Dhaka. A large number of children with club feet needed intensive, periodic intervention, which was managed through collaboration of a local therapist for assessment and plastering at an international non-governmental organisation centre and then referral for surgery to a further specialist mission hospital. 26 children with cleft lip/palate benefitted from free sponsored operations in a Dhaka government hospital. The largest group identified was the cerebral palsy children (20% of total) who need long term therapy support, which is seldom available, even at district level. In the pilot we were able to partner with a local non-governmental organisation who had three trained community disability workers. However, in the current district, this does not exist, so we are using a model of parent training.

It was essential to map all these services first, then contact and negotiate with providers to establish a referral network process beforehand so that the KIM assessment team had all the necessary information and contacts at the camps. The Community Mobilisers have an important role in facilitating and following up with families after the assessment camps as there are many barriers to the uptake of services. Even where financial and logistical support is given, only half of the families were initially prepared to take up services and fear is often the hidden reason. Further qualitative work is planned to explore the reasons for these barriers, which is essential to improve access to services.

Overall, the study demonstrated that KIM can be an effective tool in estimating prevalence for district planning as 972 children listed by KIs out of 1,272 examined, had a confirmed diagnosis of disabling impairment (75%) and the majority of the others had some form of impairment but not as severe. Having this concrete estimate of numbers and need is always a required first step to improving access to services at district level for a defined group.

KIM is also an appropriate, low cost way of case finding through community mobilisation using a sustainable network of key informants. In addition, the training workshops were a useful way of raising disability awareness issues, disseminating information and spreading more positive messages. Links were established with local Disabled Persons Organisations and non-governmental organisations who could learn from the process and increase their capacity to continue the work themselves after the KIM study. A Dhaka Task Force of disability stakeholders and providers is involved with the project to take it forward and use the results for advocacy purposes.
An appreciation of health systems when planning and developing rehabilitation services means they are more likely to succeed. However there is little evidence that the rehabilitation community has widespread knowledge of health systems, nor that it takes them into consideration. This paper will define health systems and show how rehabilitation might interact with health systems.

INTRODUCTION

Viewing health care as a dynamic system is not a new approach but has gradually gained importance in recent years. Research in various fields such as economics, ecology, bio-medicine and public health has shown that systems shape our world and societies (Bloom and Standing, 2008).

In simple terms, a health system is a system of actors that produces and organises goods (e.g. infrastructure, equipment, and drugs), knowledge (information) and services (i.e. health services) to improve the health of the population (See Figure One) (World Health Organization, 2006). A health system includes all the non-health activities (education, housing etc) and actors (organisations or individuals) that aim to have a direct or indirect impact on health. A health system can be as small as a village or cover larger scales such as a district, a region or a country.

Rehabilitation faces a major constraint: the level of use of rehabilitation services is not high enough to cover the needs of the populations. Today, most practitioners have a poor understanding of health care processes and systems because there has been limited exposure to this field. An understanding of how these health systems function makes it possible to create innovative ways of delivering effective rehabilitation services.
Health services are viewed as complex adaptive systems. Complex adaptive systems are systems that have a large number of actors that interact in ways which are not always predictable and whose actions are interconnected and interdependent. The study of ecological and human systems has already highlighted important system characteristics. Recognising these properties can help researchers and rehabilitation practitioners understand how a health system can behave following the introduction of an innovation such as a new rehabilitation programme or policy.

A complex system has the following properties:

- **Rehabilitation systems are embedded within other systems**
  In a globalised world, defining a health system has become more and more challenging due to the multiplicity of actors intervening at different scales, and the blurring of boundaries between traditional and modern medicine, and between the formal and informal sectors. Sophisticated communication technologies have also increased the size of social networks and the volume of information flows. A rehabilitation centre is embedded within a district hospital, which is embedded within a regional health care system and a national health care system. The evolution of each of these complex systems influences, and is influenced by, that of the other systems.

- **A system in constant evolution**
  In the same way as micro organisms, systems and their actors adapt to changes. To survive, systems have to cope with shocks and become resilient. This requires constant adaptation from their actors. A change to a rehabilitation intervention, like every other innovation, constitutes a critical event that has an impact on processes and dynamics between actors who constantly need to adjust.
Nonlinearity
Changes provoked by shocks and innovations might have knock-on effects also known as the butterfly effect. These shocks may be insignificant events. For example, an orthopaedic technician’s working trip to a neighbouring country might be followed by the introduction of new practices at the centre. Reading a document about new practical guidelines might lead to the introduction of new practices in physiotherapy. All these changes generated may have a major impact on rehabilitation settings and on how people work and collaborate. It is nevertheless difficult to predict the impact of such events on the system and to plan for this properly. Linear planning approaches were often criticised for not taking into account the dynamism of the context and for regulating relationships between actors in a very rigid way. The nonlinearity of how systems and people react and act requires constant changes and adaptations from planners according to what is taking place around them.

Analysing relationships between individuals helps to understand how the system behaves

WHAT CAN HEALTH SYSTEMS RESEARCH OFFER TO REHABILITATION?

Health systems research in rehabilitation is still at a nascent stage although other health sectors, such as HIV/AIDS or maternal and infant health, have already demonstrated the positive influence the strengthening of health systems has on drawing up and implementing international programmes. For example, the Tanzania Essential Health Interventions Project demonstrated the positive association between strengthening health systems and decreasing maternal and infant mortality (de Savigny, Kasale et al., 2004). Several studies have explored how the equitable provision of health services could be improved through a universal coverage scheme, conditional cash transfers for the poor or exemption from user fees for the poor (Alliance for Health Policy and Systems Research, 2004). The Joint Learning Initiative on Human Resources for Health created a major impact on international and national human resources policies by providing evidence on the additional human resources needed to obtain universal coverage (Chen, Evans et al., 2004). International rehabilitation involves a wide range of actors (e.g. patients, local providers and authorities, international organisations and donors). People perceive the same situation in different ways according to their own experience and perspective. The means that rehabilitation programmes are implemented in different systems that are relevant to and constructed by each different actor. Understanding how these different, and sometimes conflicting, perspectives can be managed to create consensus towards a common vision can help to improve the effectiveness of rehabilitation interventions. This is termed a health systems approach.
ONLY A HEALTH SYSTEMS APPROACH CAN ANSWER THE FOLLOWING CRITICAL QUESTIONS FOR REHABILITATION:

ACCESS:
► How to improve the use of and access to rehabilitation services?
► How to improve the quality of rehabilitation services?
► How to make rehabilitation services more cost effective?

PREVENTION:
► Which social networks and communication channels are the most effective for spreading information and introducing behavioural change?

PROGRAMME:
► What are the main assets and obstacles in the health system in which the rehabilitation programme is implemented?
► Does the health system provide currently provide the resources required to deliver rehabilitation services and will it do so in the future?
► How can rehabilitation services be better integrated into mainstream health systems?

MANAGEMENT:
► Can rehabilitation service managers make the right decisions at the right time to adapt to shocks?
► How to efficiently allocate the resources available within the health care system (equipment, drugs, money, human resources)?
► Is the country’s bureaucratic system an obstacle to the functioning of rehabilitation services? How can the bureaucratic constraints be reduced?

RECOMMENDATIONS
This paper describes how health systems research and the strengthening of health systems can contribute to improve the effectiveness of rehabilitation programmes. However, the strengthening of health systems can only be effective if one can create synergies amongst the majority of the actors in the rehabilitation community (i.e. national and international actors; practitioners, researchers, policy makers and donors).

The areas for consideration by rehabilitation practitioners should include:
1. **Generating evidence**: to foster synergies between rehabilitation actors to identify research and knowledge needs.

2. **Translating research into practice**: to draw up programmatic tools to help rehabilitation managers assess and measure the performance of health systems and integrate health systems as a cross-cutting component of rehabilitation interventions.

3. **Translating research into policy**: to mobilise international donors and policy makers to increase investment in strengthening health systems and drawing up more appropriate policies.
REFERENCES


ACHIEVING RESULTS

**WHO’s strategy to promote access to healthcare services for persons with disabilities.**

1. **Raise awareness**
   Raising awareness about the magnitude and consequences of impairments and disabilities.

2. **Build national capacities**
   Building capacity among health and rehabilitation policy makers, service provides and Disabled People Organisations (DPOs).

3. **Mainstream objectives into national plans**
   Supporting national efforts to promote and strengthen health and rehabilitation services for people with disabilities and their families.

4. **Promote community-based strategies**
   Promoting and strengthening community-based rehabilitation strategies.

5. **Produce assistive devices**
   Promoting the development, production, distribution and servicing of assistive devices.

6. **Foster partnerships and networks**
   Fostering multisectoral partnerships and networks.

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Kenya, 1993
ADDITIONAL RESOURCES


WEBSITES
Community Action Research into Disability (CARD) http://www.katutandike.org/index.php

ELDIS - Service delivery in fragile States http://www.eldis.org/index.cfm?objectId=D79556FE-ABAB-0D1A-8DE295BB1A58B250

International Centre for Eye Health https://www.iceh.org.uk

London School of Hygiene and Tropical Medicine http://www.lshtm.ac.uk/

Sustaining Ability http://sustainingability.org/