



Policy Paper

Support to Organisations Representative of Persons with Disabilities

Technical Resources Division
July 2011

Authors

Priscille Geiser
Stefanie Ziegler
Ute Zurmühl

Contributors

Céline Abric (Handicap International
Madagascar)
Ola Abualghaib (Handicap International
Palestine)
Soumia Amrani (Parents Association of
Autistic Children, Morocco)
Ousseini Badini (Handicap International
Burkina Faso)
Ros Bandos (Handicap International
Cambodia)
Frankin Kabba Bangura (Sierra Leone Union
of Disabled)
Philippe Chervin (Handicap International)
Giampiero Griffo (member of Disabled
People International)
Marie-Pierre Guicherd (Handicap
International)
Ibrahim Isaac Kamara (Handicap
International Sierra Leone)
Sanna-Mari Laitamo (Handicap International
Central America)
Zoltan Mihok (Center for Society Orientation
Serbia)
Mark Morrison (Handicap International
Belgium Cambodia)
Rhonda Neuhaus (Handicap International
United States)
Ngin Saorath (Cambodian Disabled People
Association)
Fredrik Stockhaus (SHIA Sweden)
Susanne Wilm (international consultant for
Handicap International in Cambodia)
Sophie Wyseur (Handicap International
Belgium)
Mastafa Zahir (Handicap International
Morocco)
Suad Zahirovic (Information Centre for
Persons with Disabilities Bosnia and
Herzegovina)

Additional comments

Eric Delorme
Catherine Dixon

Editor and technical support

Michael Guy

Graphics

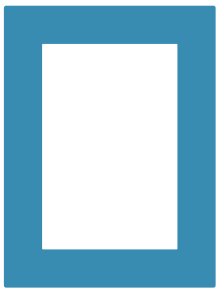
IC&K, Frédéric Dubouchet
Maude Cucinotta

Layout

NJMC, Frédéric Escoffier



This document may be used or reproduced
only if the source is cited and only for
non-commercial purpose.



Policy Paper

Support to Organisations Representative of Persons with Disabilities

Foreword 6

Principles and Benchmarks 9

Supporting Disabled People's Organisations (DPOs) as organisations representative of persons with disabilities	10
Why support DPOs?	17
Links with Institutional Framework Documents of Handicap International	24

Intervention Methods 31

Component 1: Prepare for action by developing internal capacities	38
Component 2: Promoting actions to change attitudes, practices and policies	46
Component 3: Monitoring the situation of persons with disabilities and their human rights	54
Component 4: Support the individual empowerment of persons with disabilities	62

Appendices 69

Glossary	70
Acronyms	75
Reference documents and resources	76
Major actors and websites	80
List of projects analysed	84
Footnotes	86

the 1990s, the number of people with diabetes has increased in all industrialized countries. In the Netherlands, the prevalence of diabetes is estimated to be 6.5% in 1995, which corresponds to 1.5 million people (1). The prevalence of diabetes is expected to increase to 10% by the year 2010 (2).

Diabetes is a chronic disease, and the long-term complications of diabetes are a major cause of morbidity and mortality. The most common long-term complications of diabetes are retinopathy, nephropathy, neuropathy, and cardiovascular disease. The prevalence of these complications is high, and the burden of disease is substantial (3).

The management of diabetes is a complex task, and the physician must be able to identify and manage the complications of diabetes. The physician must also be able to provide education and support to the patient, and to coordinate care with other health care professionals. The physician must also be able to monitor the patient's progress, and to adjust the treatment plan as needed (4).

The physician must also be able to identify and manage the complications of diabetes. The most common complications of diabetes are retinopathy, nephropathy, neuropathy, and cardiovascular disease. The prevalence of these complications is high, and the burden of disease is substantial (5).

The management of diabetes is a complex task, and the physician must be able to identify and manage the complications of diabetes. The physician must also be able to provide education and support to the patient, and to coordinate care with other health care professionals. The physician must also be able to monitor the patient's progress, and to adjust the treatment plan as needed (6).

The physician must also be able to identify and manage the complications of diabetes. The most common complications of diabetes are retinopathy, nephropathy, neuropathy, and cardiovascular disease. The prevalence of these complications is high, and the burden of disease is substantial (7).

The management of diabetes is a complex task, and the physician must be able to identify and manage the complications of diabetes. The physician must also be able to provide education and support to the patient, and to coordinate care with other health care professionals. The physician must also be able to monitor the patient's progress, and to adjust the treatment plan as needed (8).

The physician must also be able to identify and manage the complications of diabetes. The most common complications of diabetes are retinopathy, nephropathy, neuropathy, and cardiovascular disease. The prevalence of these complications is high, and the burden of disease is substantial (9).

The management of diabetes is a complex task, and the physician must be able to identify and manage the complications of diabetes. The physician must also be able to provide education and support to the patient, and to coordinate care with other health care professionals. The physician must also be able to monitor the patient's progress, and to adjust the treatment plan as needed (10).

“It is clear that the battle to reduce poverty will not be won by merely technical inputs or financial flows without developing a supportive civil society which can act to demand rights, transparency and good governance from the state, and to counterbalance elite controls of the economy and polity”.

John Beauclerk, Brian Pratt and Ruth Judge

in “Civil Society in Action, Global case studies in a practice-based framework”
INTRAC, 2011

Foreword

In 2008 Handicap International (HI) started developing Policy Papers for each of the major sectors in which the organisation works. These papers outline a common vision for HI, based on a review of existing frameworks for action and an analysis of practical experiences. Policy Papers therefore aim to provide a point of reference for programming, decision-making and implementation within HI. This should ensure that HI's interventions are coherent and consistent in terms of objectives and practices, whilst being flexible enough to adjust to a variety of circumstances and contexts.

This Policy Paper on “Support to Organisations Representative of Persons with Disabilities” is based on the practice and extensive experience acquired by HI in this area. **HI has been implementing projects with a specific focus on developing the capacities of Disabled People's Organisations (DPOs) since the beginning of the 1990s** and has gained significant experience of working with DPOs as partners in many countries across the world.

This experience of developing strong partnerships with DPOs as well as working with national authorities and service providers has enabled HI and its partners to influence disability rights issues at the highest level, specifically by playing **an active role in the development of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**. In conjunction with key players such as the International Disability and Development Consortium (IDDC), HI participated in the civil society group to advocate for this Convention to adopt a development perspective, as a condition to ensure impact for persons with disabilities, the majority of whom live in great poverty. HI also supported the participation of partner DPOs from the South, to ensure the voice of persons with disabilities living in developing countries could be heard in this process.

HI's motivation to support DPOs is based on the belief that **persons with disabilities themselves, as civil society representatives, must play a central role in ensuring that their human rights are translated into concrete measures** that effectively improve their lives. The overall objective of projects focused on developing the capacity of DPOs is therefore to **promote the full participation of persons with disabilities in all areas and at all levels**. In line with the general principle of UNCRPD (“full and effective participation and inclusion in society”, Article 3 and general obligation Article 4.3) and with HI's strategy¹, these projects recognise the need to engage in strategies that truly improve the participation of persons with disabilities in development processes, and the role HI can play to support these strategies².

In the context of increasing attention to disability issues (since the entry into force of the UNCRPD in 2008, disability is progressively gaining momentum on the international agenda, including among donors), HI has undertaken a global review of its pioneering work to support to DPOs, particularly in terms of practical experiences and methodologies. In 2009, HI UK³ coordinated an initial research phase to review documents from approximately **twenty-five recent projects focused on the promotion and effective implementation of the rights of persons with disabilities**⁴. A further qualitative review of these projects was then conducted

by HI Germany, concluding with the organisation of a seminar in Munich, December 2009, where practitioners met to discuss and devise common strategic approaches. Twenty-eight people (including representatives from partner DPOs, HI field and headquarters' staff) shared their experiences in supporting the disability movement and worked intensely to identify key recommendations and methodologies for action⁵.

The results of this broad exchange of know-how, skills and practices are reflected in this Policy Paper and endorsed by the participants. The authors and contributors wish that this paper encourages and supports the development of projects and initiatives that truly include the perspective of persons with disabilities to better translate their rights into reality.



“अपाङ्गतालाई विकासको
सँगसँगै जाने सवालसँग
गाँसेर कार्यक्रम
वनाइनुपर्छ ”



“अपाङ्ग
व्यक्तिहरू



“सुखी बलाक अपाङ्गता जस्ता
व्यक्तिको लागि कतिपय
विशेषता बनाएकन लाग्नु
पर्छ ।”

Nepal, 2010

Principles and Benchmarks

SUPPORTING DISABLED PEOPLE'S ORGANISATIONS (DPOs) AS ORGANISATIONS REPRESENTATIVE OF PERSONS WITH DISABILITIES	10
A. Disability models: from an individual problem to the recognition of discriminatory factors	11
Individual models of disability	
Social model of disability	
B. Organisations of the Disability Movement	12
Self-Help Groups	
Disabled People's Organisations (DPOs)	
Federations of DPOs	
C. Representing a large section of the world population	14
D. The UN Convention on the Rights of Persons with Disabilities	15
Participation of persons with disabilities in developing the Convention	
UNCRPD as a tool and roadmap for DPOs	
<hr/>	
WHY SUPPORT DPOs?	17
A. DPOs are essential actors to improve participation of persons with disabilities	18
B. DPOs play a special role in promoting inclusive development	19
C. DPOs have a responsibility to promote access to quality services for persons with disabilities	21
D. Handicap International's actions to support DPOs in these roles	23
<hr/>	
LINKS WITH INSTITUTIONAL FRAMEWORK DOCUMENTS OF HANDICAP INTERNATIONAL	24
A. Building on the social model and on the UNCRPD to improve persons with disabilities' living conditions	25
B. Enhancing participation of persons with disabilities, one of HI's goals	25
C. Connecting advocacy to concrete changes for persons with disabilities	26
D. The role of DPOs in enhancing access to services	26
<hr/>	
LINKS WITH OTHER THEMES	27

Supporting Disabled People's Organisations (DPOs) as organisations representative of persons with disabilities

Since its creation in 1982, Handicap International (HI) has been working with Disabled People's Organisations (DPOs). This work materialised through specific initiatives supported at programme level (for example, celebrating the International Day of Persons with Disabilities on the 3rd of December), but also through partnership relations and joint implementation of projects. In some projects, supporting Disabled People's Organisations (DPOs) is just a component. For example, Inclusive Local Development (ILD) projects seek to build the capacity of DPOs to work with local authorities and take part in the definition of local development priorities and plans. HI rehabilitation projects also work with DPOs as representatives of service users.

Realizing the importance of having strong allies in civil society to advance and improve the situation of persons with disabilities, HI has developed many projects with the aim of strengthening the disability movement. For approximately fifteen years now, HI has been developing projects to build the capacities of DPOs in more than 40 countries worldwide. One of the first in this regard was the Madagascar project on "Access to rights for persons with disabilities, through the creation and promotion of a structured associative movement", which later inspired a regional project in the Balkans ("Self-Help and Advocacy for Rights and Equal Opportunities South East Europe", SHARE-SEE). Building on the lessons learned and outcomes of this regional project, other national and regional projects in support of DPOs have since emerged in the Middle East, West Africa, Latin America and Maghreb⁶. Supporting national partners to develop

their capacities is a core element of a sustainable development approach. HI is engaged in the provision of technical support and capacity development for different types of organisations, to strengthen their organisational skills and capacities to fulfil their mandate autonomously. The same applies to supporting DPOs. However, to properly understand the key issues regarding support for representative organisations, it is important to understand the specificities of DPOs, how they have developed and their particular role and responsibilities with regards to the common goal of improving the situation of persons with disabilities. This is the purpose of this first section.



A

Disability models: from an individual problem to the recognition of discriminatory factors

DPOs have emerged and evolved in line with changing disability models. Models of disability are like different lenses through which one sees and understands disability and persons with disabilities. Many conceptual models have been developed that influence the various responses to disability in different societies. This part of the Policy Paper briefly recalls major evolutions in the perception of disability and how they have led to the progressive emergence of a 'disability movement'. Disability has long been considered an individual problem to be addressed *only* from a medical or charitable viewpoint. This perspective neglected the fact that persons with disabilities often suffer from discrimination, are frequently excluded from social, economic and political processes in their societies with very poor access to services and that their rights are frequently denied.

Individual models of disability

Analyses of the evolution of disability perceptions often refer to the charity and medical approaches as being most prevalent. The charity model looks at persons with disabilities with pity and calls for generosity to help them, while the medical model seeks medical/ rehabilitation systems alone and special services to 'repair the broken' or 'restore normal functioning'. Although these two models differ in spirit and proposed response, they both have a common root: **the individual with impairment is seen as the problem to be solved and responsibility for disability lies with the person who must be 'fixed'**. This view equates disability with impairment,

and "within this paradigm social exclusion is seen essentially as the result of limitations imposed by 'disabilities'".

Social model of disability: "it is society that disables us, not our impairments"

The social model of disability is born from the critique of the above-mentioned interpretations, which emerged in the 1970's in the UK and the US. It proposes an interpretation that is radically different by asserting that **persons with disabilities are disadvantaged not because of their individual characteristics but as a result of limitations imposed on them by environmental and external barriers. Disability is thus a result of how society is organised.** According to this formulation, disability is about discrimination and social exclusion. This model implicitly recognises that impairment is part of life and calls for different responses and priorities: while acknowledging and including the necessary medical interventions, the focus is placed on the removal of disabling barriers (cf. examples of barriers overleaf) that prevent the full participation of persons with disabilities and make it impossible for them to take control of their own lives.



Focus - Examples of barriers creating disabling situations

Institutional barriers: For example, when no law exists to ensure that children with disabilities can attend school.

Environmental barriers: For example, when a person cannot participate at an event due to a physical barrier such as an inaccessible public building.

Communication barriers: For example a deaf person cannot join a public debate or follow the television without a sign language interpreter.

Attitudinal barriers: For example when a health professional believes that a person with a disability is 'less worthy' or less valuable and therefore does not give the priority to this person in care provision.

Shifting the emphasis from the individual to the environment, the social model places the responsibility on society and calls for necessary environmental modifications.

It views disability as the result of an interaction between environmental and personal factors. This model is reflected in the WHO International Classification of Functioning, Disability and Health (ICF) and in the Disability Creation Process (DCP), conceptualised by Patrick Fougeyrollas, and adopted as a reference by Handicap International. It is also the one referred to in the UNCRPD and its core vision of an inclusive society, where persons with disabilities may enjoy their human rights as any other human being, without facing systematic obstacles and barriers. Article 1 of the Convention legally anchors this model by stating that "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"⁸.

B

Organisations of the Disability Movement⁹

The social model has provided a powerful framework for mobilising persons with disabilities around the idea that they should be actors in their own lives, rather than passive recipients of care. In the US and UK, individuals with disabilities started carrying out self-advocacy against discrimination and inequality and claimed for independent living and accessibility¹⁰. Moving away from individual attempts to improve individual living conditions, persons with disabilities formed their own representative organisations: thus, the first modern DPOs were founded with the goal of advocating for their own rights. DPOs progressively emerged all over the world to claim equal rights, and 'Disabled Peoples' International' (DPI) was founded in 1981 as the first international advocacy organisation of this 'new generation of DPOs' emerging out of the social model of disability. In fact, **the 'disability movement' covers a variety of associations created and led by persons with disabilities¹¹, including self-help groups, DPOs, federations and networks of DPOs.** Historically, persons with disabilities have also created organisations to engage in the provision of services to their members and this remains a significant part of DPOs' work around the world. Service provision to persons with disabilities is not unique to DPOs. **In this paper, the focus is deliberately placed on the specificity of DPOs and their core role and mandate as representative organisations.**

Self-Help Groups

Self-Help Groups (SHG) of persons with disabilities are mostly founded to share common experiences, situations or problems and to offer their members the unique perspective of peers and/ or families who have experienced a similar situation. SHG are run by and for group members to improve their lives, both socially and economically. They usually function as a peer support group and often do not have a formal structure or status. SHG of persons with disabilities are often members also of DPOs and (through election of the board) hand over the mandate to represent their interests to the DPO. As they evolve and get involved in wider scale activities, these SHG may need to become formal entities and 'transform' into DPOs.

Disabled People's Organisations (DPOs)

"In essence, a DPO is defined as an organisation that is led and controlled by disabled people."¹² Another definition suggests: "**DPOs are representative organisations or groups of persons with disabilities, where persons with disabilities constitute a majority of the overall staff and board**, and are well-represented in all levels of the organisation. It includes organisations of relatives of persons with disabilities (...) where a primary aim of these organisations is empowerment and the growth of self-advocacy of persons with disabilities"¹³. Organisations of families/ parents of persons with disabilities pursuing similar goals are also considered DPOs. DPOs support the development of persons with disabilities' capacities by providing them with a common platform to exchange and share their experiences and build a common voice. They often engage in the provision of information on disability for their members (on their rights, but also existing services,

facilities and provisions) or specific services, such as sign language training. Many DPOs are engaged in the provision of rehabilitation or socio-economic services to their members, which they consider part of their mandate (this varies significantly depending on the context). In their function of representatives of persons with disabilities, **DPOs mostly see their role as raising awareness in society and advocating for equal rights as citizens.**

Federations of DPOs

When different DPOs decide to form a network, this can result in forming a cooperation with common goals and objectives or cross-disability alliances. If the network of DPOs is more structured and establishes itself with yet another level of representation, a cross-disability federation emerges. A federation of DPOs (at national or regional level) usually has a well-defined structure and is a membership organisation with a legal status. In the majority of cases, several federations co-exist in a given country and represent the interests of a specific group (e.g. federation of deaf associations), whilst a national umbrella organisation of all federations aims to serve as unique interlocutor on behalf of all persons with disabilities. This huge responsibility emphasises **the importance of having transparent structures through which persons with disabilities can feel adequately represented**. The key role of a cross-disability federation is indeed to embody the alliance and common voice of all persons with disabilities in a given country and interact with decision-makers at the highest level. While some community-level DPOs engage in service delivery, it is important that national-level, cross-disability federations of DPOs focus only on their function of representation¹⁴.



C

Representing a large section of the global population

Persons with disabilities represent a large section of the population: the estimates this as 15% of the world population or nearly one billion people, representing the largest minority in the world. Many more people are actually directly affected by disability when considering the impact of disability on family members and carers. DPOs are the organisations that stand for this large section of the world population. **DPOs aim to be the legitimate representatives of persons with disabilities, actively advocating for their rights and finding ways to improve their situation.**

One of the main challenges for DPOs is the diversity of people they aim to represent. For example, situations experienced by people with physical disabilities may differ considerably from those experienced by people with visual or with psycho-social impairment. Their priorities are, in turn, very different. As explained above, limitations and barriers faced by people having the same disability also vary according to each individual and his/ her direct environment. Building a common voice for promoting the rights of all persons with disabilities is nonetheless essential to advancing the rights of people who all have been traditionally excluded and marginalised from society, and experience similar barriers.

Developing alliances across different disability groups is an essential way to build the legitimacy and credibility of DPOs to represent and advocate on behalf of this large section of the population.

In this perspective, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which was called for, and elaborated with, unprecedented participation from DPOs representing all types of disabilities, is a very important tool. It sets a common reference framework to

work towards the realisation of *all* human rights for *all* persons with disabilities. At the same time it integrates the “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” as a general principle.

D

The UN Convention on the Rights of Persons with Disabilities

Participation of persons with disabilities in developing the Convention

Although several documents and resolutions from the United Nations already referred to disability (cf. "focus" below), none of them were legally binding for the States, and none of them explicitly covered all dimensions of persons with disabilities' lives¹⁵.



Focus - Disability in the international agenda

1945-1960 - The UN defined disability as a physical, psychosocial and vocational limitation as a result of illness or injury and accordingly focused on social welfare and rehabilitation. Even in the 'Universal Declaration of Human Rights' the word 'disability' was mentioned merely as a vulnerability category with regard to welfare and the problem was established as one of individuals.

1970's - UN Declaration on the Rights of Mentally Retarded Persons and the Declaration on the Rights of Disabled Persons : they were the first international instruments to establish human rights principles concerning specifically persons with disabilities; however they reflected an approach of disability based on a medical and charity model rejected by DPOs who preferred a social model, recognising the role and responsibility of the environment in creating disabling situations.

1980's - With the International Year of Disabled People (1981) and the International Decade of Disabled Persons (1982-1991) proclaimed by the UN, disability was given more visibility which led to the adoption of the World Programme of Action concerning Disabled People (1982) encouraging national programmes to reach equality for persons with disabilities.

1993 - The Standard Rules for Equalisation of Opportunities of People with Disabilities are adopted. Developed along the lines of the World programme of Action, they provide a universal framework for activities to integrate the rights of persons with disabilities into national legislation and truly mark a change of perspective on disability. Not binding however, they were not sufficient to ensure that the rights of persons with disabilities would be sufficiently reflected in national and international development strategies.

13th December 2006 - Adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

3rd May 2008 - Entry into force of the UNCRPD

The first proposal for a Convention was made by Italy and Sweden in 1987, but at the time existing general treaties were considered sufficient by a majority of States. It was only in 2001 that the General Assembly issued a resolution calling for the creation of an Ad-Hoc Committee in charge of drafting the text of a Convention that would also include a social development perspective. Twenty-seven representatives of States, twelve representatives of DPOs and one human rights organisation formed a working group within the Ad-Hoc Committee and worked on a draft text which was used as the basis for discussion. Participation of persons with disabilities in the development of the document was ensured through the key role played by the International Disability Caucus in the negotiation process to maintain the final text as close as possible to the initial proposal. The UNCRPD was finally adopted by the UN General Assembly on the 13th December 2006.

Major changes brought by the UNCRPD

Most significantly, the UNCRPD:

- Does not create new rights for persons with disabilities but recalls that **existing human rights apply equally to persons with disability** and enumerates steps and actions that are necessary for their full realisation (cf. human rights approach to disability, glossary);
- Is **legally binding** for the State Parties, who have to report at regular intervals on steps taken to enforce it;
- Is **a development tool and a human rights instrument**¹⁶;
- Endorses the 'disability paradigm shift' by applying the **social model of disability** to the entire text of the Convention (cf. Article 1);
- Is a policy instrument that is **cross-disability and cross-sector**;
- Represents **"a huge step forward for the promotion of access to services** for

people with disabilities in all contexts and environments"¹⁷

- Clearly stipulates the **role of representative organisations of persons with disabilities** as a driving force in the promotion of the rights of persons of disabilities, consistently requesting their participation (cf. in particular Articles 3, 4.3, 29, 30, 32 and 33).

UNCRPD as a tool and roadmap for DPOs


DPOs worldwide make use of the Convention as an important legal basis for promoting policies and practices that are truly inclusive and accessible to them. The International Disability Alliance (IDA) emerged during the drafting of the Convention and is now the key player at international level to coordinate and advocate for the effective implementation of the Convention¹⁸.

Although the CRPD represents a major step, it is a tool that can be effective and make a difference for persons with disabilities **only if used and enacted**. This calls for all stakeholders to play their role to make these rights a reality. Although the process is not necessarily linear, key steps in using the UNCRPD as a tool to improve the situation of persons with disabilities in a given country include: signature and ratification, domestication of the UNCRPD at national level through adaptation/ review of the existing legislation, development, implementation and monitoring of relevant public policies with the corresponding budget allocations, and adaptation of service delivery systems and service provision.

In the work engaged by Handicap International for about ten years to strengthen the disability movement, support to advocate for the signature and ratification of the CRPD has been a key component.

Why support DPOs?

Now that many countries have signed and ratified this essential document (thereby acknowledging the obligations stated), **a tremendous challenge remains with transforming this 'declaration of intentions' into concrete changes that contribute to realising the rights of persons with disabilities.** Obligations of State Parties include those to “protect, promote and fulfil” the rights entailed in the UNCRPD and to report regularly to the Committee of Experts in charge of monitoring this Treaty. DPOs have a key role to play to observe, monitor and advocate for this to happen in reality. Critical for a follow-up of these steps are the mechanisms put in place by the State to ensure independent monitoring of the Convention's enforcement. DPOs have a major role to play to ensure that such mechanisms are established in accordance with **article 33** of the UNCRPD. This work includes engaging in close monitoring of steps taken by the State Party as well as in **reporting at the international level through preparing an alternative or shadow report** to complement the State's report to the Committee.



The rationale for Handicap International (HI) to engage in projects and initiatives in support of the disability movement is three-fold: (1) DPOs are essential actors to improve the participation of persons with disabilities; (2) DPOs play a special role in promoting inclusive societies where persons with disabilities' rights are fully realised; (3) DPOs also have a special role to play to enhance access to quality services for persons with disabilities. As relatively new organisations whose members often face discrimination, DPOs have often had limited opportunities to develop relevant capacities and resources. The last part of this section introduces actions engaged by HI to support these organisations to efficiently fulfil these responsibilities.

A

DPOs are essential actors to improve participation of persons with disabilities

Participation can be understood at three levels, which all are necessary and complementary:

- ▀ Participation of the person with a disability in decisions affecting his/her individual life, e.g. choosing the place where s/he wants to live, expressing preference between different options for rehabilitation, etc.
- ▀ Participation of persons with disabilities as representatives of users of services in the governance of service delivery organisation, e.g. to claim for new types of services, express quality expectations, etc.
- ▀ Participation of persons with disabilities to influence decision-making processes, policies and practices, e.g. to advocate for a disability law, or accessibility standards to be adopted, etc.

Participation of persons with disabilities is an over-arching principle of the UNCRPD (cf. following section “focus”). Article 4.3 in particular implies that participation of representatives is an obligation of States for any decision that affects persons with disabilities’ lives.



Focus - Participation of persons with disabilities as an essential ingredient of the UNCRPD

- **Preamble (o)** considers “that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them”.
- **Article 3** of the CRPD includes the “full and effective participation and inclusion in society” as one of its general principles. This means that participation of persons with disabilities cuts across the entire text and applies to the whole Convention.
- **Article 4.3** emphasises this as follows: “In the development and implementation of legislation and policies to implement the present Convention, 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”.
- **Article 29** is another important article focusing specifically on “participation in political and public life”.
- **Article 32** focuses on the participation of persons with disabilities in international cooperation ensuring that it “is inclusive of and accessible to persons with disabilities”
- **Article 33 and 35** insist on participation of persons with disabilities in the monitoring process and in the preparation of reports by State Parties.

Since its creation, HI has been responding to the needs of persons with disabilities, improving their living conditions and promoting the respect for dignity and their fundamental rights, together with a preventive action towards impairments and disabilities linked to diseases, accidents and violence. In a variety of sectors, this work consists of reducing obstacles to full participation, ensuring that persons with disabilities can access the services they require and enjoy their lives to the fullest¹⁹. This concern has been incorporated in the current strategy 2011-2015, in which “participation of persons with disabilities and vulnerable groups in the development process” is one of the five priority objectives²⁰. It has also been reflected in participatory working modalities which guide our partnerships with DPOs (see reference to participatory approaches in Part 2).

B

DPOs play a special role in promoting inclusive development

Participation of persons with disabilities at all levels is necessary to make development inclusive and thereby realise the inclusive society envisioned in the UNCRPD. Inclusive development is a direct consequence of the shift of the disability paradigm: asking societies to adapt and adjust in line with the diversity of its members. By participating in decision-making at various levels, DPOs, as representative organisations, have a specific role to play in promoting a model for development that is inclusive of, and accessible to, all persons with disabilities. Inclusive development²¹ builds on the idea of a ‘society for all’ where persons with disabilities can live their lives with dignity and enjoy their human rights on an equal basis with others. This is a common goal for HI and DPOs²².

Inclusive development implies a double action or **twin-track approach**²³ to ensure that:

- **Disability is included in all mainstream development programmes** with the aim that “the rights of persons with disabilities are part of all development programmes, from planning and design through monitoring, implementation and evaluation”, and
- **Specific actions are taken** to support persons with disabilities and their organisations in recognition of the fact that the removal of barriers alone will not create inclusion for persons with disabilities. There is also a need to ensure that persons with disabilities can receive adequate specific support (e.g. an assistive device, personal assistance). “Mainstreaming is not the only answer. At the same time there must also be specific focus on disabled persons and disability issues to enable persons with disabilities to become empowered participants (...). Conditions should be created to foster individual empowerment of

persons with disabilities from birth onwards (to develop maximum functioning), and to facilitate the formation of organisations from the community-level upwards”²⁴.

This means that while strengthening the disability movement to promote the rights of persons with disabilities is necessary, this should never be disconnected from the perspective of an inclusive society where persons with disabilities participate on an equal basis with others. **The point is not to have specific rights but to ensure that specific actions are taken for the enjoyment of the same human rights.** This requires coordinated actions between DPOs, decision-makers and service providers.



Focus - Why it is important to work with DPOs, statements from HI Country Directors

“In Kenya we are working hand in hand with local and regional DPOs and national DPOs. The impact we see is not mainly on the short run but it will make our work more sustainable on the long run. Working in advocacy activities together with DPOs as partners we have more emphasis than as HI alone. Furthermore the network of DPOs called UDPK, which includes all kinds of disability, has the possibility to reach out to people in areas where HI is not present. We all want an inclusive society and without the DPOs as representatives of persons with disabilities this is not possible”.

Alphonse Kananura, Country Director, Handicap International Kenya

“Persons with disabilities are still invisible in the mainstream development field of Afghanistan. DPOs, as civil society actors standing for persons with disabilities, represent a huge potential for both improving the quality of development in Afghanistan to make it inclusive, and providing the support needed to establish a disability movement. They should ultimately be able to represent persons with disabilities without the support of foreign organisations. Yet the capacities of the DPOs remain weak, as well as their ability to coherently promote disability rights. Misconception about disability and its causes and power related dynamics, among certain DPOs based on ethnicity or type of impairment, make the cooperation among the organisations more difficult and therefore their advocacy less powerful. Therefore support and work still needs to be done.”

Arvind Das, Country Director, Handicap International Afghanistan

C

DPOs have a responsibility to promote access to quality services for persons with disabilities

As explained above, the human rights reaffirmed in the UNCRPD do not mean much as long as they do not translate into **concrete changes in the lives of persons with disabilities**. An essential part of inclusive development consists in **ensuring that persons with disabilities can access to all types of services on an equal basis with others**. This implies also access to specific services, oriented towards optimising the participation of persons with disabilities.

Building on nearly 30 years of experience in service delivery, HI has decided to prioritise access to services for persons with disabilities as a core priority for the period 2011-2015. This systemic approach gives a significant place to persons with disabilities as users of services, and the role of their representative organisations to demand, choose and evaluate the quality of services. The work of DPOs indeed contributes to **improve the adequacy, relevance and quality of services provided by including the user's perspective**.

Optimizing access to services for persons with disabilities implies that all concerned stakeholders, including government authorities, service providers and DPOs, play their role in the process. As representative organisations of persons with disabilities, DPOs need to engage in the interplay between the key actors responsible (see "focus" overleaf) to: (1) advocate with the authorities and claim for services, systems, policies that are inclusive and accessible and (2) to utilise and take part in the design, monitoring and evaluation of both mainstream and specific services (quality control), together with service providers. Their voice is essential to reflect an expertise on disability from people

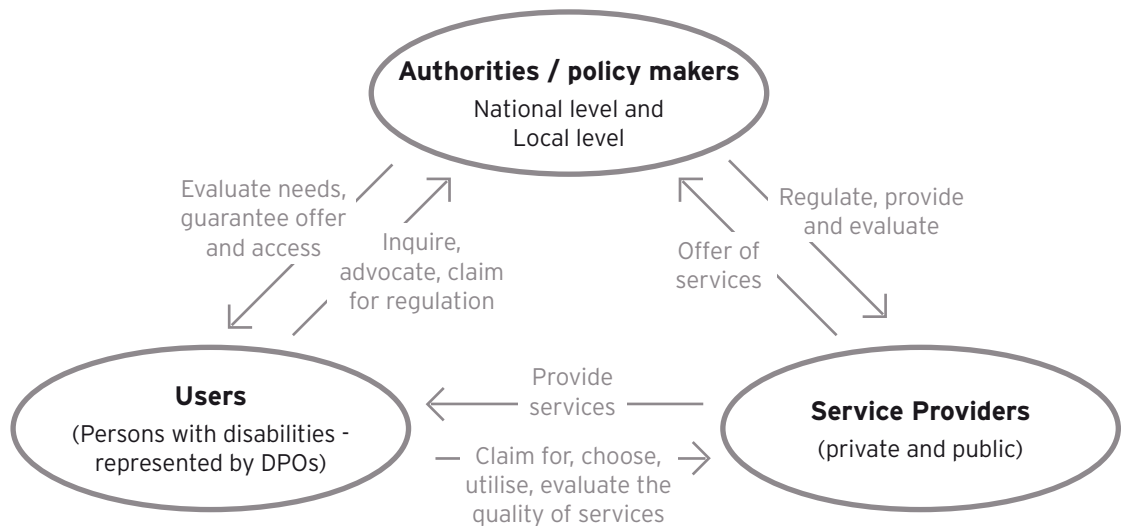
who experience a service, which can be complementary to the expertise of disability professionals.

Wherever HI is involved in development actions, DPOs are therefore important stakeholders to work with to achieve common objectives. It is expected that this support to DPOs as representatives of users of services will be reinforced in HI actions.



Focus - Access of persons with disabilities to services: roles and responsibilities of stakeholders.

Fig. (a) Good collaboration between the three types of stakeholders presented below is important to ensure access of persons with disabilities to services. If DPOs do not play their role, the whole system cannot function successfully²⁵.



D

Handicap International's actions to support DPOs in these roles

After many years of experience of working in the disability sector, HI has observed that in most developing countries there is a discrepancy between the important role that DPOs have to play and the limited opportunities, resources and capacities they have had to fulfil this role. Throughout the world, there are more and more DPOs, which are developing and getting progressively more structured. However, many obstacles remain. **Support needs have been identified in four major areas**, which are key components of projects implemented by HI to support the disability movement in fulfilling the three above-mentioned roles:

1) In low or middle income countries where the majority of persons with disabilities live²⁶, the fact that persons with disabilities are usually denied education opportunities has significant impact on the capacities of their representative organisations. DPOs very often struggle with **organisational and technical weaknesses** while lacking financial and human resources. This situation limits their efficiency and impact. Some DPOs need support to develop stronger democratic governance practices and strengthen their legitimacy to represent persons with disabilities. Stronger cohesion between existing DPOs (e.g. between organisations representing people with different types of disabilities) is also necessary to optimise their capacity to act jointly on a common disability agenda. In this perspective, HI brings the wealth of its long experience in capacity development of partner organisations from the South to help DPOs develop internal capacities (component 1).

- 2)** In developing countries, DPOs often have not had the opportunity to complement their practical, daily experience of disability with the knowledge of new conceptual models of disability (developed at the international level). Understanding these models is necessary to explain disability, analyse patterns of discrimination and advocate for change. Moreover, DPOs often need to improve their capacity to mobilise people to bring about change. **Awareness-raising and advocacy both require strategic skills and a clear knowledge of the roles and responsibilities of policy makers and service providers** that DPOs can develop to increase their efficiency. HI therefore intervenes to support the disability movement in developing advocacy capacities and joining forces with other civil society movements (component 2).
- 3)** Another key area of involvement for DPOs is the monitoring of persons with disabilities' situation and the actual enforcement of their rights. A major tool for this is the UNCRPD which serves as a reference on the obligations of States Parties to take concrete steps to make the rights of persons with disabilities a reality. **As newcomers to the human rights field, many DPOs have little concrete experience using the human rights monitoring mechanisms and structures.** They need to be in a position to monitor that the rights entailed in the Convention are adequately reflected in national policies, and further translate into changed practices that impact on persons with disabilities' lives. To this end, HI supports DPOs to engage in studies and other methods to document the situation of persons with disabilities in their country and initiates the production of reports based on field practices that can be utilised by DPOs for advocacy²⁷ (component 3).

Links with institutional framework documents of Handicap International

4) Due to stigma and marginalisation, persons with disabilities often remain invisible in society. Facing multiple barriers (e.g. communication, environmental, attitudinal), persons with disabilities often have a lower self-esteem and need reinforced confidence and skills to engage in public work. They sometimes struggle to be recognised as credible, legitimate and necessary interlocutors. It is consequently challenging for DPOs to efficiently play their role as civil society actors. This can be further reinforced in the contexts of developing countries where the civil society as a whole is weak and not experienced in negotiating with government and other stakeholders. To be more efficient and break this negative circle, DPOs need to engage in **actions to empower their individual members**. With its many years of experience in supporting persons with disabilities through a person-centred approach, HI can support DPOs in this process, for example through establishing information and referral mechanisms (component 4).

These four dimensions are key focuses for HI projects supporting the disability movement. The actions to address these needs are detailed in Section 2.

HI strategic documents, namely the Principles of Intervention, the Scope of Activities and the Strategy 2011-2015, provide the rationale for HI to engage in supporting DPOs.



A

Building on the social model and on the UNCRPD to improve persons with disabilities' living conditions

HI has adopted the Disability Creation Process as a model for defining and explaining disability²⁸. This recognises the importance of the social model and of environmental factors in creating disabling situations, and consequently the need to act on societal barriers (attitudinal, communication, institutional, environmental barriers) to improve the lives of persons with disabilities. This model calls for actions with DPOs as representative organisations capable of addressing environmental factors in the long term through extensive advocacy.

The UNCRPD is an important document "on which we can now draw to justify and implement our actions"²⁹. It is one of the reference documents which can serve as a tool "to remind governments and international organisations of their duties and responsibilities, and thereby contribute to improving the offer of services for all persons with disabilities"³⁰. For the period 2011-2015 in particular, "HI will draw on the provisions of the UNCRPD to support national stakeholders with projects for influencing the development of local or national laws and policies, in order to improve the provisions they contain or their implementation"³¹.

B

Enhancing participation of persons with disabilities, one of HI's goals

Projects supporting DPOs contribute to achieve one of HI's key goals which is to "strengthen capacities, promote social participation and the application and exercising of our beneficiary public [i.e. persons with disabilities]'s rights"³². Here 'participation' is acknowledged as both:

- a working modality: "We seek to involve beneficiaries, their families and communities, and support solidarity mechanisms within the community"³³
- an objective: "Inclusive development is a subject common to all Handicap International's long-term programmes. During the period 2011-2015, the focus will be on increasing the participation of beneficiaries and their representative organisations in development processes at various levels"³⁴

C

Connecting advocacy to concrete changes for persons with disabilities

A characteristic of HI's work to support the disability movement (detailed in part 2) is to develop DPOs' capacities in a way that connects their advocacy actions with direct impact on persons with disabilities' lives. As a 'field practitioner' organisation, HI's Principles of Intervention specify that "our action is implemented primarily at local level and at the services level, alongside the populations, groups and individuals concerned. This ground-level experience gives us legitimacy in seeking a greater and more lasting impact through working to influence systems and policies"³⁵. This approach is also applied in HI's field-level support to DPOs, which are encouraged to develop strong connections between advocacy work and concrete practices that impact on persons with disabilities: evidence of good practices can reinforce advocacy work, and advocacy needs to be oriented towards obtaining real outcomes for people. What HI recommends to its partners are working methods that are similar to those it applies to itself: "[advocacy] aims to promote a political environment that is favourable to improving the living conditions of the beneficiaries of our action and to the exercising of their rights"³⁶.

D

The role of DPOs in enhancing access to services

More specifically, this connection between advocacy and outcomes for persons with disabilities also materialises through HI's concern for improved access of persons with disabilities to all types of quality services. Projects supporting DPOs contribute to "support (...) our civil society partners in convincing authorities of the need for access to quality services"³⁷. As the first place people with disabilities often turn to for help and support, DPOs are also one of the actors HI engages with in "efforts on producing effective solutions and models for informing the persons concerned about the existence of services, how to access these services and their rights to access"³⁸.

Links with Other Themes

There are many important references and approaches, central to the work of Handicap International, that have been addressed in this paper in a cross-cutting manner. For connections between strengthening of the disability movement and the Disability Creation Process (DCP), the UNCRPD, access to services and inclusive development, please refer to part 1 of this document. Other, more specific notions, such as lobbying, empowerment, the human rights approach to disability, are detailed in the glossary.

The existence of a strong disability movement contributes significantly to strengthening a wide range of interventions, ensuring they adopt a human rights approach to disability. Linkages with other thematic areas or sectors of HI are briefly addressed below:

➤ **Access of persons with disabilities to specific and mainstream services:** participation of persons with disabilities in the design, governance and evaluation of any type of service is central to the realisation of their human rights, through improved access to quality services. This concerns all sectors (health and prevention, rehabilitation, education, livelihoods, social activities, etc). In rehabilitation centres for example, DPOs or groups of users can play a role in ensuring that services are adapted to the people they target, with regards to quality standards, physical accessibility, adequacy of services delivered to individual needs and wishes, attitudes of professionals, involvement of the person in the rehabilitation plan, etc. Strengthening DPOs is therefore beneficial and complementary to interventions in specific service sectors³⁹.

➤ **Community-Based Rehabilitation (CBR):** the WHO/ILO/UNESCO 2004 Joint Position Paper on CBR, as well as the 2010 CBR Guidelines, both reaffirm the

importance of associating DPOs in the design, implementation and evaluation of CBR strategies. The Empowerment Component of the CBR Guidelines⁴⁰ also proposes orientations to work on advocacy and communication, community mobilisation, enhancing political participation, Self-Help Groups, and DPOs. CBR is now seen as one strategy to ensure that provisions entailed in the UNCRPD become a reality for persons with disabilities from national to community level.

➤ **Inclusive Local Development (ILD)⁴¹:** ILD is a strategy that aims to promote the participation of persons with disabilities at the local level, including strengthening DPOs to take part in local decision-making. ILD projects are particularly useful in demonstrating that participation of persons with disabilities is not only possible, but also beneficial for the entire community. ILD provides opportunities for local DPOs to exercise their rights as civil society actors, for example through taking part in the preparation of inclusive local development plans or local disability action plans at municipality level.

➤ **Inclusive Policies:** Disability-related policies (public policies or policies of development actors) need to be developed in close coordination with representatives of persons with disabilities. In line with UNCRPD articles 4.3 (participation in policy and decision-making) and 32 (international cooperation), the purpose is to engage DPOs and mainstream (governmental or non governmental) development actors into accessible and inclusive development planning, implementation, monitoring and evaluation to ensure that development equally benefit to persons with disabilities⁴².

➤ **Emergency interventions:** Handicap International has developed an expertise

in ensuring that emergency responses also reach persons with disabilities (in accordance with UNCRPD article 11). DPOs, when they exist prior to the emergency, are essential interlocutors to identify persons with disabilities, their needs and priorities and to provide recommendations for adequate response strategies.

▀ **Mine action:** Victims of mines and other explosive remnants of war (ERW), through their own organisations or through cross-disability representative organisations, have a critical role to play at sub-national, national and international levels. This can include advocating for the rights and needs of victims (and other persons with disabilities); raising-awareness of at-risk populations at community level on the dangers of mines/ERW, (including cluster munitions) and advocating with their local government representatives⁴³. The role of DPOs is also key in providing precise information on the socio-economic impact of mines/ERW at community-level that often supports the funding, design and implementation of demining, risk education and community liaison activities. With increased donor interest in victim assistance strategies, DPOs may find increased opportunities to advocate for the rights of persons with disabilities.





Senegal, 2010

Intervention Methods

FAVOURABLE CONDITIONS AND APPROACHES TO ENGAGE IN SUPPORT TO DPOs	31
<hr/>	
PROJECT COMPONENT 1 - PREPARE FOR ACTION BY DEVELOPING INTERNAL CAPACITIES	38
Developing organisational capacities	40
Strengthening capacities to efficiently represent and advocate for persons with disabilities	41
<hr/>	
PROJECT COMPONENT 2 - PROMOTING ACTIONS TO CHANGE ATTITUDES, PRACTICES AND POLICIES	46
Developing strategic interventions	46
Working modalities	49
Examples of actions	50
Measuring advocacy	51
<hr/>	
PROJECT COMPONENT 3 - MONITORING THE SITUATION OF PERSONS WITH DISABILITIES AND THEIR HUMAN RIGHTS	54
Monitor and document the situation of persons with disabilities	55
Monitoring policy and law enforcement	57
Gather evidence-based good practices and develop recommendations	59
<hr/>	
COMPONENT 4 - SUPPORT THE INDIVIDUAL EMPOWERMENT OF PERSONS WITH DISABILITIES	62
Engage in service delivery?	62
Contribute to members' empowerment	63
Serve as an information and orientation platform	64

This part presents the operational modalities that serve as a reference for HI to implement projects in support to DPOs. First, an analysis of favourable conditions and strategic working approaches to engage in this type of work is presented, drawing on ten years of experience of working with DPOs in very different contexts. Key components of projects are then presented to guide project design and implementation. These correspond to strategic areas of intervention and can be adapted to devise logical frameworks.

Favourable conditions and approaches to engage in support to DPOs



Focus - Working with DPOs in various environments

Analyse the environment and identify allies

Analyse the political environment

The political and human rights situation and the dynamics of the civil society are strong determinants of the possible scope of action for HI and DPOs in a given country. Environments conducive to the free expression of civil society movements are favourable conditions for the success of projects supporting the disability movement. This was the case in Brazil, where the dynamism of social movements was a motivation for the disability movement to take a place in the social and political scene. Challenging environments should not prevent HI from getting involved in such work (cf. following section “focus”), however situations should be carefully assessed to avoid unnecessary risks, especially in countries where civil society expression is highly controlled.

Favourable political environment

As recently assessed by Vida Brasil and its partner organisations, political developments in Brazil following the elections of Lula have created a favourable environment for DPOs. Openness to dialogue, establishment of mechanisms for participatory democracy and the possibility for DPOs to identify persons with disabilities to fill positions within authorities all contributed to obtaining significant successes, such as the creation of a Permanent Accessibility Commission within the State of Bahia. However, interacting with a ‘friendly power’ has also created challenges for DPOs who are not necessarily as united as they would be against a ‘common enemy’.

Challenging political environment

Having gone through a long period of civil war, Nepal is characterised by its authoritarian leadership and an unstable political environment in the immediate post-conflict period. Despite competing priorities on the national political agenda, such as securing peace, developing new institutions, demobilising army and Maoist fighters, the disability movement managed to obtain the signature of the UNCRPD due to the context that allowed for unprecedented expression of civil society voices.



Focus - Examples from the field

Build broad coalitions and alliances

Human rights are indivisible and apply equally to all human beings. When engaging in the promotion of the rights of persons with disabilities, it is important to remember that these are not disability-specific rights. By realising the linkages with other social groups, DPOs can build alliances and coalitions to advocate jointly for the respect of their human rights. HI's approach has been to promote two major types of cooperation:

- Mainstreaming disability in advocacy initiatives conducted by other discriminated groups: for example, women's groups need to realise that there are also women with disabilities among them; persons with disabilities can take part in other social movements advocating for human rights through recognising their multiple identities: being a person with a disability but also a black person, a woman, a member of a low caste group, an inhabitant of an isolated or poor area, etc.
- Utilizing strengths and experience of other civil society movements to strengthen the disability movement, which is very often one of the newest movements. In Brazil for example, persons with disabilities have learned from the movement on social, economic and cultural rights; in West Africa, cooperation with women's organisations has enabled DPOs to learn about the process of monitoring an international Convention.

An inclusive society in which everyone can feel respected and have equal chances cannot be built in isolation.

In **Brazil**, this cross-cutting approach to promoting human rights has led to the establishment of alliances through the Civil Commission for Accessibility of Salvador (Comissão Civil de Acessibilidade de Salvador, COCAS) and significant achievements have been made to make the city of Salvador more accessible. DPOs have also taken part with other groups in the monitoring of the Treaty on Economic, Social and Cultural Rights.

In **Sierra Leone**, the Lobby and Advocacy Group, composed of DPOs and mainstream NGOs, has been instrumental in debating strategies on how to best promote the rights of persons with disabilities in a moment where the national federation of DPOs was going through a leadership crisis.

Essential approaches to programming

Working at different levels

When planning projects in support to the disability movement, it is important to analyze which level/s are the most relevant to target.

- Actions at the **local level** are particularly relevant to support DPOs to engage in consultations for developing inclusive local development plans and **acquiring hands-on experience of participation in local governance**. A clear advantage of working on a local scale is the proximity between decision-makers and the local population, and hence the shorter distance between decision-making and concrete results/changes for people.
- Working at the **national level** offers opportunities to call for change at State (institutions) or government level (legislation, public policies). **Implementation of the UNCRPD** through relevant mechanisms, legislation, policies and budget allocation is the major issue at this level.
- Initiatives and exchanges between several countries in a same region refers

Favourable conditions and approaches to engage in support to DPOs

to another possible level. Experience has shown that it is beneficial for DPOs to share their national experiences, challenges and solutions and to feel they are part of a wider **regional dynamic**. It also **strengthens their legitimacy** to engage in dialogue with national level authorities.

Experience has shown that **combining interventions at several levels** offers real added value. It contributes to strengthening the disability movement as a whole, it increases the accountability of national level federations towards their members at lower level, and tends to promote improved sharing of information to grassroots level (cf. text on DECISIPH below). This approach of working at different levels encourages cooperation, solidarity and mutual understanding. Importantly, **it avoids projects only achieving national level objectives that do not impact on the lives of persons with disabilities**, or impacting on a very small number of persons with disabilities without setting examples at a broader level.

As a 'field practitioner', HI favours projects that systematically include outputs at the local level, often in the form of pilot actions that demonstrate tangible results and benefits for persons with disabilities and society.



Focus - The DECISIPH project in West Africa: linking local, national and regional levels to optimise impact

The DECISIPH project aims to interlink interventions at three levels and this has proved to be particularly effective. The approach is based on the observation that the national level is often disconnected from the regional and/or local levels. Representatives and leaders from the capital city do not know well enough the reality of the rural area, while local level disability groups often have little knowledge or visibility on developments at the national level. The DECISIPH project has taken up the challenge to contribute to building stronger bridges between these levels.

For example:

- **Local:** DPOs have been supported to engage in consultations with local authorities to put disability on the local development agenda. In Mali (Village of Didieni) DPOs have influenced the municipality to financially support a system of motorised ambulance ('moto-ambulance') that ensures persons with disabilities' access to emergency health care. The success of this practice is now being taken to the national level, with an ongoing analysis of how this local practice can be replicated at a broader scale.
- Through the **regional** exchange opportunities created by the project, this example of good practice has been shared within other countries of the sub-region.

Adopting participatory approaches

Adopting a participatory approach is essential for any project aiming to support the disability movement. In order to improve the participation of persons with disabilities in development processes, projects need to start by incorporating this strategic methodology at each stage of project cycle management. HI has extensive experience of ensuring participatory approaches in a variety of different sectors (e.g. through approaches such as the Community Approach to Handicap in Development), and this has proven very effective in building the ownership of DPO partners on the project, and thereby improving the sustainability of actions undertaken⁴⁴. Another key point is that HI is not an organisation of persons with disabilities and does not have the legitimacy to speak on their behalf. In the process of rapidly constructing projects and programmes, this participatory component is sometimes underestimated and not given enough time and emphasis. Experience has shown that project design which neglects the participation of partner DPOs for defining common goals can lead to frustration, mistrust and can jeopardise project results. Tools and methods for participatory programming and management of projects exist and need to be incorporated as part of all projects – processes are as important as results (cf. reference documents and resources, Appendices).

Key elements of the relationship between HI and DPOs

Define appropriate and evolving modes of cooperation

HI's involvement in supporting DPOs has taken various forms, from informal collaboration to joint engagement on specific actions or fully-fledged projects. In each situation, the relationship established, as well as the objectives of the collaboration will vary. With reference to Alan Fowler's terminology⁴⁵, HI and DPOs can be 'development allies' exchanging information and experience to achieve a common agenda, in a loose type of relationship. In HI projects where support to DPOs is only a minor component, the role of HI might be closer to that of a 'project funder' or a 'programme supporter'.

In projects that aim at strengthening representative organisations of persons with disabilities as key players for building an inclusive society, there is an increased **concern about the organisational capacity of DPOs**. The focus is placed on the relevance, efficiency and sustainability of the organisation. This means that HI acts more as an 'organisational supporter' to DPOs, while this relationship still entails programme support: projects supporting the DPO movement should never disconnect organisational capacity development from its real purpose, i.e. efficient representation, advocacy and support to help persons with disabilities live a better life. Neglecting this may lead to supporting organisations that become empty shells. Conversely, neglecting organisational capacity development will jeopardise sustainability of the work undertaken when HI withdraws.

The relationship between HI and DPOs usually undergoes several stages. In the beginning, the emphasis is often placed on a capacity development process, financial resource provision and the development of

Favourable conditions and approaches to engage in support to DPOs

technical competencies of DPO staff. One objective is to make this relationship evolve towards a trusted and sustainable partnership for implementation of complementary activities under mutual goals; another objective is the empowerment and complete autonomy of the DPO, i.e the withdrawal of HI from the existing partnership in the long term.

Ensure a clear distribution of roles and responsibilities

One key element is a relationship where roles and responsibilities of both the DPO and HI are clearly defined at the time of project design. Many frustrations or difficulties can emerge due to unrealistic objectives or expectations and a different perception of each other's role. To put it in simple terms, **HI's role is to act as a supporter, while DPOs represent the voice of persons with disabilities and engage in actions where this legitimacy is required** (e.g. advocacy or policy monitoring). In reality, one must deal with the complexity caused by unbalanced technical capacities and financial resources. One critical point in this regard is the respective weight in decision-making, i.e. DPOs legitimately representing the target group and Handicap International being ultimately accountable to the donor for achieving the project results. During the HI Munich workshop in 2009, participants all agreed that cooperation between HI and DPOs is more effective and successful if the parties concerned **establish a comprehensive agreement about how they intend to co-operate.** This usually takes the form of a Project Steering Committee with clear rules defining decision-making mechanisms and operations (cf. following section "focus"). The rationale being: more transparency at the beginning of a cooperation means less confusion will arise afterwards. Therefore the process of developing such an agreement should be taken seriously and allocated sufficient time.



Focus - The role of a Project Steering Committee

Advantages of a Project Steering Committee

In the Balkans, the SHARE-SEE project was led by a Regional Steering Committee comprised of five core partners: the Association of Students with Disabilities Serbia (ADS), the Centre for Independent Living Serbia (CIL), Handicap International (HI), Information Centre Lotus BIH (IC Lotos) and Polio Plus Macedonia (Polio+). The role of the SHARE-SEE Regional Steering committee was:

- to define project policy and strategy and decide adjustments
- to coordinate regional exchanges
- to pilot the Regional Disability Observer
- to organize a summer school
- to contribute to the information system design and maintenance
- to select grantees for micro-projects
- to carry out the cycle assessment

Some tips for the successful functioning of Project Steering Committees in projects supporting DPOs

According to project stakeholders, the Steering Committee was fundamental to the success of the Share-SEE project. Key elements to its successful functioning included:

- **Strong mutuality and complementarities between partners' and HI:** for example some partners were very good in media advocacy, others in community work, or relations with local government etc. It is important that each member brings an acknowledged expertise or added value and a strong identity which allows for a balance of power in the committee. It is also crucial to have a common vision on approaches to disability and goals so that debates and discussions are focused on implementation but not on fundamentals.



- **Transparency and co-ownership:** HI was the lead applicant and responsible for the funds and this was very clear from the beginning. Budget was transparent, partners knew how much HI was investing in, and getting from, the project. The share of the budget for activities directly under the responsibility of the steering committee was subject to equal co-decisions and HI didn't have a veto (except when incompatible with donor regulations).
- **Successful doesn't mean smooth:** if there is a real co-ownership it is likely that tensions or conflicts will be more open as the relation is safe and sure. Experience has shown that partners would often contribute to ease and resolve the tension between themselves or towards HI. Successful doesn't mean smooth - it means meeting the purpose.
- **"It is our work but it's their lives":** Some of the decisions made by the Steering Committee were the partners' decisions and were not considered strategic or advisable by HI. However, it is their country, their societies, their members and their colleagues. They will bear the consequences, positive or negative, of their decisions, more than HI does. HI always gave its point of view, sometimes in a stronger way than others, but mostly supported partners' decisions. Ownership is the key for empowerment and empowerment is not an easy road, neither for the one in process nor for the one who supports it.

Define the scope and limits of the collaboration

Support to organisations as a strategic focus needs to be envisaged in a well-defined timeframe. DPOs should progressively become autonomous in handling their responsibilities as representatives of persons with disabilities, and not develop an operational dependency on HI. While HI can encourage and facilitate the formation of new organisations or support the development of existing self-help groups, DPOs or federations, experience has shown that it is preferable not to engage directly in creating organisations from scratch. Similarly, it is strongly recommended to **envisage the end of the supporting phase at project design stage**. Early definition of an exit strategy or the evolution of support phases to guide DPOs towards autonomy avoids the possibility that efforts undertaken are wasted because the donor support has ended. This forward planning prompts DPOs to be more proactive in identifying ways to sustain their activities⁴⁶.



**Focus - Lessons learned from Madagascar
Project design and relationship between HI and DPOs: lessons learned from Madagascar**

In 2000, the Madagascar programme focused its support to the DPO movement with the objective to reinforce their organisation at local level and to create a national federation (COPH: Collectif des Organisations de Personnes Handicapées) for improved representation and lobbying at national level. Although projects initiatives were a success overall and contributed to the emergence of a disability movement in the country, results were mixed with the following limitations:

- Creation of the federation was decided at national level and not initiated or pushed from the grassroots.
- This creation was seen as the objective and capacity development was not given sufficient importance. When it existed it was based on HI expectations more than on the DPO's project.
- Roles and functions at each level were not sufficiently defined, creating tensions and misunderstandings, in particular between national entities and local associations.
- At the local level, the project supported the creation of new associations in areas where they did not exist, however the incentive was mainly external and most of them have never functioned correctly.
- HI took a strong leadership in the project, directly looking for funding for local DPO projects and giving little visibility to DPOs. In fact, relations developed throughout the project reinforced DPOs' dependency on HI.

Project Component 1 - Prepare for action by developing internal capacities

Component 1 relates to capacity development of DPOs, with the intention to improve the quality of representation of persons with disabilities. Engaging in social participation through advocacy and awareness-building is more likely to succeed if DPOs have good organisational capacities, a representative basis, and sufficient expertise on disability.

Generally, two main elements are recurrent in capacity development: it always consists of a process and content. Capacity development is a complex and context-specific process of enhancing existing capacities, which requires a coherent long-term strategy and continuous adaptation to the specific context and situation (capacity development plan). When it comes to the content of capacity development, it is important to examine what the organisation is (its identity and culture, mission and strategy), what it does (activities, projects and programmes), what keeps it financially running and how it relates to other actors in the sector (in particular, primary beneficiaries, donors and other stakeholders).

The two key approaches of HI are therefore:

- the development of organisational capacities of DPOs and
- the strengthening of their function as representative organisations.

Therefore HI supports the following activities:

- **Training:** Training DPO members at various levels (local, regional, national) is a way to strengthen the disability movement as a whole and to avoid a top-down development of capacities. However, for all training to strengthen the capacities of DPOs, one must keep in mind the risks associated with the possible turn-over of



Focus - Training, Counselling and Consultancy sessions (TCC)

DPO members and leaders. This, ensuring sufficient participation in training (at least 3 staff per DPO) reduces the loss of knowledge due to staff turnover. Having the person “endorsed” formally by his/her organisation to participate can also be a way to inform other members and prepare for further horizontal sharing of information within the DPO.

➤ **The transfer of knowledge:** Formal training is only one way of strengthening existing capacities of DPOs. Having flexibility in the methods to transfer skills and knowledge allows for better results (cf. following section “focus”).

➤ **A “learning-by-doing” approach:** (in real-life conditions) has proved a successful complement to training. Fundamentals are on-the-job support, consultancies within DPOs, linking training with other project activities or allocating tasks between two training sessions for trainees to experiment in practice their newly acquired knowledge.

➤ **The exchange of information and experiences:** Study tours or **exchange** trips between DPOs also demonstrated positive learning impact, but only when carefully prepared (targeted visits, sharing of information and replication of practices planned upon return, etc. - cf. “focus” on DECISIPH project).

Training materials, transportation, venues and methodologies should always be **accessible to persons with different types of impairments, with local languages used when required.**

The SHARE-SEE project provided Training, Counselling and Consultancy sessions (TCC) in order to enable DPOs to develop skills, knowledge, attitudes, values and creative actions necessary for the development of their individual and organisational capacities that will lead to social change. TCC was used as a flexible mechanism and a support system to strengthen the capacities of the disability movement: The TCC tool box presents a set of training materials, techniques and services offered to DPOs, to be chosen by DPOs as per their needs. TCC intervenes through:

- **Peer counselling:** transfer of skills and knowledge through coaching and mentoring from one DPO to another, sharing of good practices and facilitating the integration of grassroots DPOs into the disability movement;
- **Training:** formal in-house training aimed at providing the required knowledge and skills;
- **Consultancies:** providing specific technical assistance in project activity implementation or organisational development efforts; consultancies imply an effective transfer of skills in a result-oriented manner.

A

Developing organisational capacities

Organisational self-assessment as an initial step

In order to find out where a DPO stands, its strengths, weaknesses and specific needs, an organisational assessment is necessary at the beginning of each cooperation between HI and a DPO. This provides the baseline against which objectives can be set and progress measured. Through guided organisational self-assessments, organisations recognise their own potential and decide for themselves how to best address the challenges they face and how to take charge of their own development. It is therefore important that this process is conducted by DPO members, with facilitation support from HI when necessary. **Tools for organisational 'diagnosis'** exist in abundance; a selection is presented in the practical guide "Capacity development and partnership: overview and methodology"⁴⁷. Components of organisational capacities that usually need particular attention and strengthening for DPOs are detailed in the next paragraphs.

Strengthening capacities of DPOs to manage projects efficiently

DPOs need adequate organisational structure to be efficient. This refers to organisational / structural capacities in general, including management, administration, finances and project cycle management. Any training should be based on the results of the (guided) organisational self-assessment and areas prioritised by the DPO. However, the specificity of HI's approach is to insist particularly on **project management skills**, strengthening the DPOs' capacities at each step, from project planning to implementation, monitoring and evaluation. This is not specific to DPOs and general training modules have been developed by HI to support partners in proposal writing, reporting and other activities.

A key purpose of this is to increase the capacities of DPOs so that they are able to develop relevant strategies and activities and raise funds to implement them. In particular, **calls for micro-grants** to run small advocacy activities as part of HI's projects to support DPOs is a practical way of **learning by doing**. It provides an opportunity for DPOs to use the acquired knowledge and receive continued support throughout the process.



Focus - Call for micro-grants: learning by doing⁴⁸

Support to innovative initiatives from DPOs through micro-grants was one of the four pillars of the SHARE-SEE project in the Balkans. This scheme was organised in the following way:

- Launch of a call for proposals in the six countries/regions covered by the project
- Provision of consultancy sessions to short-listed organisations in order to develop full proposals
- Final selection of the applicants' proposals by the Project Steering Committee
- Organisation of a training for grantees related to project implementation and reporting;
- Signing of the contract and beginning of micro project implementation
- Supportive monitoring and consultancy during project implementation period provided by HI Country Program Officers
- Support for preparation of periodical and final narrative and financial reports

The support provided by the project to grantees during the Micro-Grant application and implementation phases, was greatly appreciated by DPOs and helped developing a real sense of partnership. The micro projects were often the first visible advocacy intervention conducted by DPOs at municipality level. The initiatives were successful in getting the support of local authorities and relevant institutions on the issues raised by DPOs and opened constructive dialogue with decision-makers. The value of results obtained is highly significant as compared to the small sum of money invested.

"I see three essential objectives for the Micro-Grant Component: First, it gives small DPOs a perspective beyond survival; secondly, it offers them a chance of learning by doing; and thirdly, it is an opportunity for DPOs to implement the project's spirit and vision" (SHARE-SEE core partner staff).

B

Strengthening capacities to efficiently represent and advocate for persons with disabilities

Encouraging good associative governance within DPOs

A specificity of DPOs is their function as spokespersons of persons with disabilities. As they speak "on behalf" of their members, it is essential that mechanisms delegating this voice are transparent and well-defined. HI therefore supports DPOs in improving their **associative governance**, through clear mechanisms of election, decision-making, representation, information sharing, training of members on democratic principles and functioning as a civil society organisation. The quality of these governance mechanisms is closely linked to the capacity of DPOs to efficiently represent persons with disabilities, to appear as credible and trusted representatives and to attract members. **Accountability to members and dissemination of information** to them is a key issue. Experience has shown that holding back important information (for example at the level of national federations) may lead to conflict and disunity.

Environmental obstacles can hinder the flow of information, for example if members live in remote areas and have limited access to transport and means of communication. Adapted methods of information flow must therefore be carefully worked out (cf. following section "focus"), incorporating all accessibility concerns.

HI's work in this regard consists of training and providing on-the-job support in order to help DPOs better define their mission (for example supporting self-help groups to develop into DPOs), expand and diversify their membership (representing people with all types of impairments), develop associative life and structure their network.



Focus - Supporting information flow to improve accountability to members

In **Togo**, HI works closely with the National Federation of DPOs called '**FETAPH**', representing approximately 30 DPOs and NGOs. For many years, member associations complained about the lack of information and communication from the executive office of the FETAPH; in particular associations located in remote rural areas had no means of communication or transport in order to access other areas with better facilities. Therefore HI facilitated a workshop on "duties of the executive office of a federation and those of its members" with representatives of member associations, staff of the FETAPH executive office and the FETAPH board participating. HI also took part in an extraordinary general assembly with all member associations, the staff of the executive office and the FETAPH board where they had a heated and extensive discussion about the "rights and duties of member association of the FETAPH". Additionally, HI employs a Liaison Officer who is responsible for the cooperation between HI and the FETAPH, advising the executive office and supporting the implementation of specific projects. Today, even if there is no specific evaluation of results, all persons concerned agree that the quality of communication within the network has improved.

Developing DPOs' expertise in new models and approaches on disability

Although they are comprised of persons who have a personal experience of disability, DPOs and their members often lack opportunities to develop their knowledge and understanding of new disability models and related rights and legal instruments. Unintentionally, DPOs can therefore contribute to sustaining charity model approaches. This issue is quite critical with regards to the mandate of DPOs to raise awareness and advocate for the rights of persons with disabilities and promote an inclusive society. Training that can complement their practical experience of disability is therefore necessary to equip DPOs with relevant knowledge and critical arguments to better explain disability. Developments in the field of disability at the international level, such as the emergence of the social model, the entry into force of the UNCRPD and inclusive development are essential references on which DPOs should become expert. As an international actor and field practitioner, HI can share this knowledge and experience to applying these theoretical references in practice. As this expertise needs to be widely shared and used by an within DPOs, a training of trainers approach seems particularly appropriate, including didactic abilities and teaching methods.

Strengthening DPOs' capacities as civil society actors

Complementary to an understanding of disability as the 'content' and subject of DPOs' work are the methods, tools and skills to convey their message. DPOs need to acquire strong skills in awareness-raising, advocacy, training, public speaking, mobilization of the media, and then use these tools in a strategic manner according to the context and expected changes. Other civil society actors already use these methods: resorting to in-country training resources can be an opportunity to build bridges with civil society groups representing other marginalized segments of society.

Calls for micro-grants to implement advocacy actions have proved particularly efficient for supporting DPOs to engage into such work after receiving formal training (cf. explanations on call for micro-grants above and reference documents and resources, Appendices).



**- Summary of Project Component 1 -
Objective: Strengthen capacities within DPOs**

Examples of expected results:

- DPOs are efficient and legitimate organisations coordinating their efforts to represent the interests of persons with disabilities
- The abilities and skills of DPOs, in terms of internal management and organisation, advocacy and awareness-raising at the national and local levels has improved.

Examples of activities:

- (Guided) organisational self-assessment / diagnosis
- Training, consultancies, peer organisation counselling or ToT to cover: administration & finance management, fundraising, project cycle management, associative governance, democratic practices, internal and external communication, advocacy and awareness, public speaking and negotiation skills, disability and human rights, monitoring and evaluation, inclusive development and the role of DPOs in access to services
- Micro-grants scheme: call for proposal, selection, support for implementation, monitoring and evaluation of micro-projects conducted by DPOs

Examples of indicators:

- A plan of action resulting from a participatory organisational self-assessment process is developed by each DPO covering the organisational level (capacity development plan) and the operational level (planned projects and activities)
- The different bodies of the DPO know about and fulfil their different roles (members, board, general assembly, executive staff, etc.): minutes of meetings, reports
- A constitution (statutes, by-laws) exists and is known by staff/members
- The DPO creates an organisational chart with job descriptions for each position

formalising the official structure of the organisation; additionally, a sociogram exists to make the informal relationships between members / staff within the DPO visible.

- DPO members / staff have improved capacities in project management/ admin finance/ advocacy/ disability... as confirmed by pre- and post-training tests or the follow-up system of trainings
- Improved fund-raising capacity and diversity of funding as compared to baseline (situation at the beginning of the project): budget amount and lines, number and type of projects, names and numbers of donors, etc.
- Improved organisation of DPOs as compared to baseline (situation at the beginning of the project): frequency of meetings, clear procedures developed and applied, transparent decision-making mechanisms, audit... (minutes, constitution/ statutes/by-laws, manual, etc.)
- Clear mechanisms are developed and function to share information between the DPO/ federation and its member/ member organisations: communication plans, reports, minutes of specific meetings, etc.
- % of micro-projects proposed by DPOs adequately meet the criteria of the call (inclusive approach, project writing skills, etc): report of steering committee / jury
- The DPO improved its networking: list of contacts and visits, minutes of specific meetings, partnership agreements, contracts, references in external documents, etc.



Senegal, 2010

Project Component 2 - Promoting actions to change attitudes, practices and policies

Whilst the first project component looked at how HI projects can prepare DPOs to play their role, project components 2, 3 and 4 are more focused on joint actions to be undertaken by DPO partners with the support of HI in order to achieve meaningful results for persons with disabilities. DPO capacity development should not be isolated from actions that contribute to the promotion and realisation of persons with disabilities' rights in concrete terms. In practice, it is not always easy to distinguish between advocacy and monitoring, however this document tries to separate actions that aim at obtaining changes (Component 2) from actions that aim at observing and documenting the situation of persons with disabilities (Component 3).

A

Developing strategic interventions

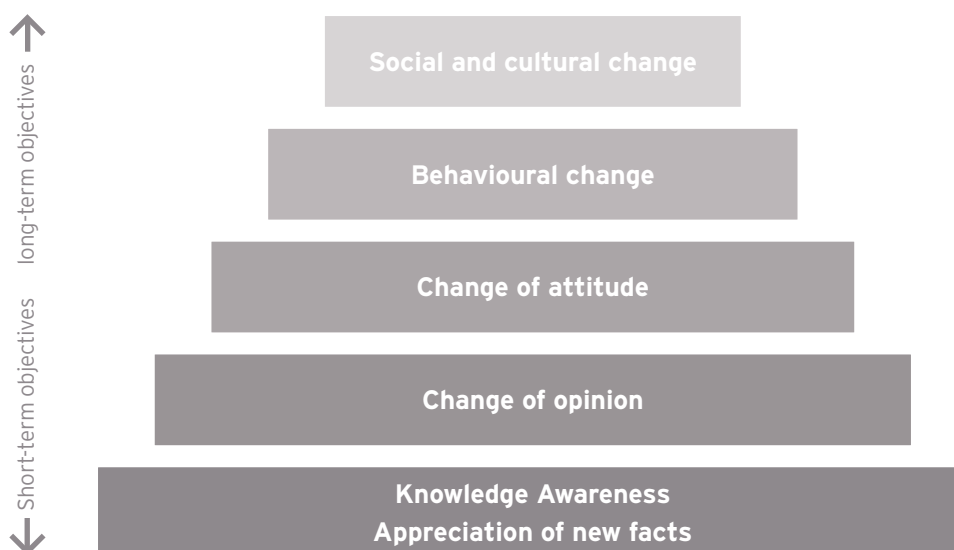
A variety of possible actions

The range of actions that promote changes in attitudes, policies and practices regarding disability issues and persons with disabilities is extremely wide. There is no model but rather each action needs to be carefully planned according to the context, existing opportunities, desired change, targeted audience and available resources.

Possible outcomes/ changes obtained do not require the same investment and timescale and it is important to be aware of what can realistically be achieved within a certain time period (see graph below).



Fig (b) Objectives of social intervention strategies



Analysis of the context

First of all, **a good understanding of the context, rules and stakeholders** is necessary for small scale or wider scale initiatives alike. This consists of mapping power dynamics, identifying who does what, decision-making mechanisms (official and informal as there is often a discrepancy between the planned system and its application in reality) and existing levers to bring about change. It also implies to identify current and upcoming **issues on the decision-making agenda**, their potential impact on the lives of persons with disabilities, and actors at stake to influence these processes. For example, at the local level, DPOs need to understand the responsibilities of local authorities, they should be aware of consultation processes with civil society actors, and they need to be informed about the next renewal of the local development plan.

Identification of priorities and development of an advocacy plan

Too often, advocacy is negatively perceived as a 'soft' type of activity, where methods are ad hoc, and results uncertain. If actions are not planned carefully, outcomes of advocacy work may well be diminished and this negative perception confirmed. Therefore strategic planning of advocacy is a key factor for its success.

Advocacy issues should be prioritized in line with:

- (a) their expected impact for persons with disabilities: indeed, **advocacy always needs to be connected to the objective of improving the situation of persons with disabilities**. The HI approach focuses therefore on advocacy for rights, such as the right to work, the right to obtain orthopaedic devices, the right to education, etc
- (b) existing opportunities in each context and period, as per the situation analysis mentioned above (it must be clear whom to influence and what policies to change)
- (c) broader needs of the community / society to avoid concentrating on specific DPO's interests.

Advocacy is a project in itself: carefully defined objectives and target groups; indicators to measure to what extent results have been achieved; corresponding actions and a timeframe; appropriate methods and tools; identified resources including possible allies, etc. Each action should find a place within a coherent plan and ultimately contribute (directly or indirectly) to realizing the rights of persons with disabilities.

Project Component 2 - Promoting actions to change attitudes, practices and policies

Fig. (c) - Advocacy circle



One generally speaks about a 'campaign' when a conjunction of different actions at various levels all aim to achieve the same goal. Each action may use different methods and tools but these should be selected carefully according to each situation.

– **Examples of possible stakeholders**

to target: government authorities, the media, public and private service providers, opinion makers, development actors, the general public, etc at different levels (local, provincial, national, regional);

– **Examples of possible methods and**

tools⁴⁹: awareness-raising, theatre, media campaign, demonstration, taking part in consultations to influence decision-making, etc.

B

Working modalities

Emphasise the positive, seek equal (and not specific) rights

Advocacy is about building alliances to bring an issue onto the agenda and influence decisions. HI's experience has shown that constructive advocacy activities such as negotiation, alliance building, the use of media, networking, convincing, etc should always be preferred to actions that violently confront opponents. HI does not engage in this type of action and does not support such actions by DPO partners.

Often, the approach to fighting for human rights focuses on human rights violations and what is not working in society. DPOs who have advocacy experience will often only advocate primarily utilising human rights abuses and what the government or other stakeholders are not providing (e.g. no education for disabled youth ; no accessible transportation, etc). However, complaining and focusing on negative aspects could well block positive attempts to change a situation. It is often more efficient to come up with pragmatic and realistic recommendations. This is the perspective adopted by **the Making It Work methodology: instead of focusing on human rights violations and what is not working, attention is shifted to what does work and how it can be replicated or 'scaled up'**⁵⁰.

All actions seeking to promote change on disability issues should use the UNCRPD as a tool⁵¹ and act towards fulfilling this vision of an inclusive society. This means targeting equalisation of opportunities (including through reasonable accommodation and specific support) rather than claiming to obtain privileges for persons with disabilities. For example, obtaining tax-free car importation for persons with disabilities does not contribute to eliminate discrimination nor

does it promote the enjoyment of their rights on an equal basis with others.

Take part in decision-making through consultations

As the UNCRPD touches on all areas of life and creates obligations for States to adjust their legislation, it is important for DPOs to monitor that this is done effectively through participating in decision-making. In line with article 3 and 4.3 of the Convention, persons with disabilities and their representative organisations are expected to bring in the perspective of their members. In democratic societies, consultations with civil society actors are organized and it is important for DPOs to take part. For example, taking part in the elaboration of inclusive local development plans has proven an efficient practice to influence decision-making (cf. ILD Policy Paper and tool to develop a local disability action plan).

Interact with authorities

Relationships between DPOs and decision-makers are at the heart of advocacy strategies and need to be managed carefully. A fine balance needs to be maintained between building friendly relations and securing support or commitments from authorities while staying autonomous at the same time. In some countries, the fact that DPOs receive funding exclusively from the government has transformed them into semi-governmental organisations with limited scope for advocacy or constructive criticism. Getting DPO members elected in influential representation functions (e.g. mayor, Member of Parliament, secretary of the municipal council, etc.) can be strategic to ensure constant alertness on disability issues (when designing policies, when prioritising issues on the development agenda, etc.). However this does not replace consultation with DPOs as civil society actors; these roles should not be confused.

C



Focus - Examples of actions

Advocating for an inclusive Poverty Reduction Strategy Paper (PRSP):

Bangladesh

The process of establishing a Poverty Reduction Strategy (PRS) in Bangladesh started in 2001 and resulted in the publication of an interim PRSP (I-PRSP) in March 2003. In the beginning, only a few civil society organisations (e.g. ActionAid and WaterAid) were involved into the PRS-process. In early 2002 an NGO meeting took place, where these organisations presented the PRS process and the issues that needed to be addressed. The way the I-PRSP treated disability shocked participants: only one part dealt with persons with disabilities, and this simply read **“we will take care of difficult social cases, such as persons with disabilities”**.

This prompted NFOWD, the “National Forum of Organisations Working with the Disabled” (comprised of 176 member organisations) and HI to publish a **joint position paper** taking the ILO paper (ILO, 2002) as a main source. The team added sections on human rights and an analysis of the national I-PRSP, selected parts that mentioned the term “disability”, and proposed improvements. NFOWD then made it possible to present the paper – and specifically a three-page summary in the national language, Bangla (the original was written in English) – to key persons in the Planning Commission of the PRS within the government and to donors.

This summary was extremely useful as a large number of people read it. In 2004 the government organised one national and six regional consultations. NFOWD pushed its member organisations to participate in the regional consultations. All of them used the translated version of the position document

as a reference, and advocated the same issues at the regional level. Due to this broad involvement, it became impossible to ignore the issue of disability.

However, NFOWD had to make a substantial effort to get itself invited to the national consultation. This was quite large (with more than 200 participants), and there was little time to present the issue. The government officially adopted the full version of the PRSP only in October 2005 even though not all ministries had accepted the content of the paper. The World Bank and IMF approved the paper in December 2006.

As a result of the joint efforts, the PRSP of Bangladesh includes now a fair number of aspects on disability (see Government of Bangladesh, 2005, pp. 157-58). A separate chapter with two pages has been included under the heading “Ensuring Participation, Social Inclusion and Empowerment”.

Unfortunately, most of the proposed actions have not yet been implemented.

Source: <http://www.making-prsp-inclusive.org/en/4-case-studies/42-bangladesh.html>

Kenya: the right for persons with disabilities to access services included into the new Constitution

Handicap International together with its main partner United Disabled Persons of Kenya (UDPK) has actively been involved in negotiating the new Constitution of Kenya, which has been approved in May 2010. Although Kenya has had a Disability Act since 2003, the first drafts of the new Constitution had not referred to persons with disabilities at all. Different umbrella organisations advocated in a broad campaign to promote the inclusion of persons with disabilities' rights into the Constitution. A common action plan (to define who would contact who on what issue in relation to paragraphs of the draft Constitution) contributed to the success

D

Measuring advocacy

of advocacy actions with stakeholders on national and regional level. Actions were planned accordingly in a constructed and strategic manner. **The new Constitution of Kenya now recognises the rights for persons with disabilities and in particular the right to access to all places, public transport and information** (Braille is specifically mentioned). The State is also obliged to ensure that minorities and marginalized groups are represented in governance and to provide access to employment and opportunities in educational and economic fields.

Advocating for Inclusion of persons with disabilities into local development plans:

Example of East Pikine, Senegal

The **local development consultation framework** of East Pikine was created to promote conditions for concerted and participatory development. It is composed of local networks and federations of organisations from the municipality. The DPO of Pikine joined the framework following its creation in 2001. As a result of this collaboration, **different activities have been developed to respond to the needs of citizens with disabilities**. These include: the creation of a vocational and basic literature training centre run by the DPO; launching income generating activities and the schooling of children with disabilities. Additionally the Chairwoman of the woman's section of the DPO has now been appointed to the position of Technical Advisor for the mayor in relation to disability issues.

Measuring the outcomes of advocacy actions is essential to review what worked and what did not and to analyse internal and external factors (cf. advocacy circle above). A first level of analysis consists of **observing changes that follow - in the short or mid-term - advocacy actions undertaken through the project**. This can help to plan follow-up actions as the context evolves to optimize the chances to get any claims answered.

Another level consists of evaluating the impact of an advocacy strategy with regards to the participation of persons with disabilities (this needs a baseline study of the situation either before or at the beginning of activities). This approach is in line with HI's current five-year strategy which places measurable impact at the core of actions. A collection and analysis of existing monitoring and impact assessment tools and methods is planned for the coming years as part of a broader reflection on the impact of HI projects in support to DPOs. Specificities of measuring the impact of advocacy include:

- The **need for long-time interventions**: societal change is a long process that requires sustained efforts
- The **multiplicity of factors** involved that need to be analysed: internal/ external, facilitators/ obstacles
- The need to **measure participation of persons with disabilities at the collective level**, i.e. through democratic mechanisms of representation: not all persons with disabilities can be individually associated to decision-making processes but they can express their concerns through a representative organisation

Project Component 2 - Promoting actions to change attitudes, practices and policies

The Brazilian Association “Vida Brasil” has developed a “participation index” tool which can be helpful in this regard. It consists of assessing the changes obtained within the concerned period and giving a mark to determine how this impacted the level of participation of DPOs: 0: worsened significantly, 1: worsened a little; 2: stagnated, 3: improved a little, 4: improved significantly. HI is currently looking into how this tool could be further utilized for projects.



- Summary of Project Component 2 - Objective: Promote actions to change attitudes, policies and practices

Examples of Expected Results:

- Stakeholders (define which ones: local administration, INGOs, etc) better understand persons with disabilities, their rights, abilities and situation and modify their practices to make them inclusive
- The general public is aware of persons with disabilities' abilities and rights
- DPOs are able to adopt and implement advocacy strategies in the field of... at national/ local level
- DPOs have acquired capacities to mobilize resources contributing to changing practices

Examples of activities:

- Awareness-raising activities using different mediums (theatre, TV and radio spots, posters, demonstrations...)
- Training of key stakeholders (journalists, governmental representatives, etc.) on disability issues and use of proper terminology
- Support to stakeholders to make their practices/ services accessible and inclusive for persons with disabilities (for example 'testing' a building's accessibility)
- Participation in existing forums (consultation opportunities) with other civil society stakeholders
- Workshops with decision-makers to mobilise them on disability and get public commitments
- Forums to inform authorities about existing discrimination and propose recommendations
- Creation and facilitation of a multilateral consultative committee (composed of DPOs, services suppliers, national or international development NGOs) to provide recommendations on policy implementation
- Take part in working sessions to develop strategic development/ poverty reduction documents to advise on inclusion of disability issues (INGO's country strategies, national plans of actions, UNDAF, CAP, PRSP...)
- Making key documents widely accessible: translations in local languages, Braille, etc; short summaries of long documents; formulation of statements; etc.

Examples of indicators:

- Disability is included in local development plans
- State and non-state development/ humanitarian actors include disability in their agenda and develop related policies
- Laws or policies (new or amendments) integrate recommendations from DPOs
- Legal provisions concerning persons with disabilities are better enforced: reports, minutes, etc.
- A consistent advocacy plan is implemented in a coordinated manner among DPOs and other civil society actors on... including at least XX events (workshops, forums, meetings, campaigns, etc) : reports
- DPOs members are new formal members of at least XX formal decision making structures/ bodies
- DPOs are systematically consulted for development/ review of the policies and programmes that concern them: list of contacts, visits, etc.
- At least one DPO per district / department / zone is represented in a steering committee of the PRSP

Project Component 3 - Monitoring the situation of persons with disabilities and their human rights

Component 3 relates to the various actions that DPOs should engage in to investigate the real life situations of persons with disabilities and produce relevant knowledge and information about how to improve it. While in the previous section the focus was placed on advocacy as a strategy to bring about changes, the perspective here is the **monitoring of these changes**, to gather information that can reinforce and/or reorient advocacy work. The two are very closely linked, as effective advocacy requires evidence-based information.

help DPOs to understand problems more clearly, to design better interventions, to make practice more effective and to monitor their results. HI has been supporting DPOs to gather the required information in a way that builds their recognition as a source of expertise and increases the likelihood that their suggestions are implemented.

'Evidence' refers to an indication of the basis for knowledge and belief. It encompasses any systematic process of critical investigation and evaluation, data collection analysis and codification, and also action research, related in this case to disability and persons with disabilities in a given context.

Policy and practice which are informed by evidence are likely to produce better results: "better utilization of evidence in policy and practice can help policymakers identify problems, understand their causes, develop policy solutions, improve policy implementation, and monitor strategies and performance"⁵².

Better use of evidence by DPOs can help to increase their influence on policies and the impact of their work. One key reason for this is that evidence enhances DPOs legitimacy; and legitimacy matters when it comes to policy influence. While representing persons with disabilities can give weight to DPOs, the use of rigorous information can also increase their 'technical legitimacy'. Evidence can also

A

Monitor and document the situation of persons with disabilities

Make the situation of persons with disabilities visible

Decision-makers often ask for information on persons with disabilities before they take any action. Why put disability on the agenda if persons with disabilities are perceived as an insignificant part of the population? Why worry about their rights if they are perceived as not able to vote (and therefore not part of the potential electorate) for politicians? **“The lack of comprehensive and up-to-date statistical information on disability contributes to the exclusion of disability from the political agenda and makes it very challenging to build effective reforms around this issue”⁵³.**

Too often it serves as a pretext for not addressing disability issues. Disaggregated data on disability is necessary to convince policy makers that disability cannot be neglected, to make informed decisions and to devise relevant programmes to support persons with disabilities. Statistical data can also be used to measure how the situation improves over time.

DECISIPH in West Africa: Key focus on access to information to support advocacy efforts

Possible methods to document evidence on the situation of persons with disabilities

Various methods can be used:

- DPOs can mobilize the national bureau of statistics to **get disability-related questions included in the national census or in thematic national surveys**⁵⁴; indeed it is the responsibility of the State to collect information on the general population, including on persons with disabilities (cf. UNCRPD Article 31)
- DPOs can partner with other specialists to undertake **epidemiological surveys**
- DPOs can also partner with sociologists or anthropologists to conduct **surveys on perceptions of persons with disabilities** in a society; a particular focus can be given to the group of stakeholders that will be expected to change their practices: for example targeting civil servants (cf. example of the DECISIPH project in the box below) or the media, as was the case in Bosnia and Herzegovina, Montenegro and Serbia⁵⁵
- With more modest resources and on a local scale, DPOs can engage in **local participatory diagnoses**⁵⁶ with the purpose to mobilize local authorities and community stakeholders into a joint analysis of the situation experienced by persons with disabilities in their neighbourhood
- Information on disability can also be collected in administrative recording and registration systems (population registers, disability pension registration systems, rehabilitation programmes registries...) where they exist and are considered reliable.

Project Component 3 - Monitoring the situation of persons with disabilities and their human rights



Focus - Collecting information on the situation of persons with disabilities in West Africa

DECISIPH in West Africa: Key focus on access to information to support advocacy efforts

The DECISIPH project aims to promote the rights of persons with disabilities through supporting DPOs' advocacy work. A central place has been given to ensure that relevant and reliable data on persons with disabilities and their rights are made available and accessible.

In this perspective, the project has conducted several activities which helped produce a broad basis of information and knowledge on disability, the situation of persons with disabilities and their rights. In particular:

- **Survey on perceptions of disability by public administration and local authorities' civil servants:** to analyse the existing negative perceptions and attitudes towards persons with disabilities and to produce recommendations to address their exclusion from society;
- **Epidemiological survey:** produce reliable data on the situation of persons with disabilities through quantitative survey in targeted localities;
- **Survey on Inclusive Local Governance:** identifying good practices in inclusive local governance and producing recommendations for action (cf. more explanations on Making it Work in the paragraph below)

All studies and surveys were conducted in 6 countries of the region with both country-level reports and a compiled regional-level report. This comprehensive approach - producing reliable information on the situation of persons with disabilities with 'different lenses' - has supported DPOs in their advocacy work, and national workshops organized to release the reports were great occasions to build ownership and mobilize stakeholders on disability issues.

Important aspects of data collection need to be considered:

- Critical to the design of statistical indicators is the definition of disability: the prevalence rate can indeed vary significantly depending on the threshold⁵⁷
- Measuring disability prevalence should not be done without gathering information on the living conditions of persons with disabilities
- It is important to have statistics that compare persons with disabilities with people without disabilities: this provides information on indirect levels of discrimination such the disadvantage of children with disabilities in accessing school as compared to other children.

B

Monitoring policy and law enforcement

Legislation and policy review

Surveys on the situation of persons with disabilities provide essential information to bring disability or a specific aspect of persons with disabilities' situation on the political agenda. However, to ensure that the government as well as private stakeholders play their part in creating a society that is inclusive of persons with disabilities, it is also important to gather information on existing laws and policies produced and enforced by these actors. As the broad framework that a country sets to itself on a given subject, laws and policies are key instruments to influence in order to get **high-level incentives for changes in the long-term and on a large scale**. Analyzing disability-related laws and policies is a necessary step to advocate for new laws, improvements or the removal of discriminatory provisions. In a second step, the implementation of existing laws and policies demands a consequent monitoring: even brilliant documents are useless if they are not translated into daily life (see also further below: UNCRPD monitoring).



Focus - Example of legislation and policy review in Cambodia

In Cambodia the project '**Mainstreaming Disability in Development Policies**' has conducted a study on *Disability, Legal Obligations and Policies in Cambodia*.

The objectives of the research were:

- To collect information on what the Royal Government of Cambodia is committed to provide to persons with disabilities (main legal obligations and policy commitments)
- To contribute to public awareness on disability, legislation and public policies, by promoting inclusion and supporting advocacy efforts of persons with disabilities.

The study supported the identification of existing legislation and policies in Cambodia and specifically related to the education, health and employment sectors. It assessed the inclusion of disability in these texts and whether provisions were supportive or discriminatory.

The study provided a basis for identifying priority areas for action by the disability movement in Cambodia, and also supported the development of relevant communication materials towards persons with disabilities and the government to be used by the project.

Project Component 3 - Monitoring the situation of persons with disabilities and their human rights

The role of DPOs in UNCRPD monitoring
In countries where it has been ratified, the UNCRPD provides a new framework to voice these concerns at the international level, specifically by writing an alternative report to the one submitted by the State Party before the Committee on the Rights of Persons with Disabilities in Geneva. Even if a country has ratified the Convention, and even if the government has recognized that disability cuts across all sectors of development and therefore should be an integral part of all national planning, its practical application often remains a challenge. **It is thus a permanent responsibility for DPOs to monitor that the UNCRPD is fully reflected in legislation, that public policies are designed with sufficient resources allocated to implement them, and that they do actually impact on persons with disabilities' lives.**



Focus - Monitoring UNCRPD enforcement through the compilation of an alternative report⁵⁸

The text of the UNCRPD includes the description of international level monitoring mechanisms. A Committee of Experts (the Committee on the Rights of Persons with Disabilities, hosted by the OHCHR in Geneva) examines reports submitted by each State Party in which they account for the status of and measures taken towards UNCRPD enforcement in their country. In such reports, States are likely to present what they have done and to disregard what is yet to be done to fully realise the rights of persons with disabilities.

It is therefore critical for DPOs to engage at the earliest opportunity in comprehensive monitoring and reflect an accurate, documented analysis of the situation. It is the responsibility of DPOs to monitor that all human rights are experienced by all persons with disabilities, to report on discrepancies and provide recommendations. Articles 33.3 and 35.4 emphasise the importance of civil society involvement in the monitoring process and State report.

This alternative (or shadow) report is reviewed by the Committee of Experts and provides its members with a fuller picture of the situation, which later influences the formulation of its recommendations (that are constraining for the State).

In practice, DPOs need to engage in the review of existing legislation and policies, to identify existing discrimination and analyze the impact on persons with disabilities. With the support of the International Disability Alliance, HI has recently trained partner DPOs to better understand and navigate these important human rights procedures. The role of HI in this process: HI does not engage directly in the production of either the State or the alternative report on

C

Gather evidence-based good practices and recommendations

UNCRPD implementation. Its role consists of:

Supporting DPOs to understand the process and methodology for producing this report

Facilitating contacts between DPOs and other civil society groups who have already engaged in such process

Initiating the production of reports (e.g. Making it Work) where information can be used to prepare or complement the alternative report.

Despite the focus on the UNCRPD, other human rights instruments should not be neglected. In particular the non-discrimination provisions of the various human rights treaties apply to all including in the context of disability. For example, General Comment 5 of the Committee on Economic, Social and Cultural Rights reaffirms that the rights entailed in the International Covenant on Economic, Social and Cultural Rights should be enjoyed by all without discrimination, extending to discrimination on the basis of disability. Hence in human rights monitoring as in other areas, the twin-track approach (including the disability perspective in mainstream instruments and monitoring the disability-specific UNCRPD) remains relevant.

Traditional advocacy work in the human rights field consists of denouncing violations, using the media and adopting a confrontational approach. As a development actor⁵⁹, HI's preferred approach and added value lies in the documentation of good practices and suggestions for their replication. This has been centrally integrated in the development of Making It Work as a global initiative to capture good practices on 'what works' to make the UNCRPD a reality.

As both a knowledge management and an advocacy initiative, Making It Work has developed a methodology and clear guidelines to **identify good practices, validate them in a collective manner (multiple stakeholders involved), extract constructive recommendations from these practices and use them strategically to advance the rights of persons with disabilities.**

HI programmes can utilise the Making It Work methodology to carry out stand-alone documentation and advocacy projects or can integrate this approach within broader projects. The purpose of this global-level initiative is to contribute to promote change at the level where this methodology is applied as well as to serve as a good practices database on implementation of the UNCRPD.

The Making It Work website (www.makingitwork-crpd.org/about-miw/) includes guidelines and toolkits to apply this methodology. It also presents good practices and reports by projects which have used this methodology (section "MIW projects").

Project Component 3 - Monitoring the situation of persons with disabilities and their human rights



Focus - Using the Making It Work methodology to advocate for an accessible city in Guatemala

As part of a regional capacity building project for DPOs in Central and South America (“Cultivando capacidades para cosechar derechos”) managed by HI in coordination with Inter-American Institute on Disability and Inclusive Development (IID) and RIADIS, the Latin-American network of DPOs and their families, El Colectivo de Vida Independiente of Guatemala’s developed a Making it Work project. The chosen topic was ‘Promoting good practices to reach personal mobility of persons with disabilities in the metropolitan area of Guatemala’, focusing on accessible transportation, UNCRPD Articles 20 (liberty of movement) and 9 (accessibility).

The aim of the project was to influence the authorities of three municipalities to increase their commitment to gradually incorporate the norms of accessibility and universal design in plans and local policies concerning the constructed environment and transportation.

The project utilised the Making It Work methodology through the following activities:

Collecting good practices of accessible transportation, specifically concerning good legislation and policies

Documenting examples of effective technical solutions and meaningful participation of DPOs in the process (case studies were gathered in other Latin American cities, such as Bogota (Colombia), San Jose (Costa Rica), Quito (Ecuador) and Curitiba (Brasil))

Analysing the information using a multi-stakeholder approach with CPAT (Political Committee for Accessible Transportation), a coalition of DPOs and NGOs who have previously participated in advocating for accessible transportation)

Writing recommendations for the municipal

authorities in alliance with other DPOs
Publishing the good practices and recommendations in a final document, aimed at the authorities of three municipalities in the metropolitan area.

This study on good practices now forms the basis for ongoing advocacy activities with the local authorities (information meetings, press conferences, forum on accessible transportation). Written agreements with the municipal authorities are about to be signed, to strengthen their commitment to working on behalf of persons with disabilities.



- Summary of Project Component 3 -
Objective: Monitor the situation of persons with disabilities and their human rights

Examples of Expected Results:

- Information on the situation of persons with disabilities and their human rights is compiled, analysed and made available
- DPOs actively engage in the monitoring of persons with disabilities' human rights, through preparing regular reports on the situation of persons with disabilities
- DPOs are part of a system for monitoring and evaluation of access to services
- DPOs are recognised as legitimate sources of information on disability (testimony, life history...)

Examples of activities:

- Comparative review of existing legislation and policies against the UNCRPD
- Research, epidemiological survey, sociological / anthropological survey on the situation of persons with disabilities
- Collect and analyse good practices demonstrating how practically the UNCRPD can be implemented (using the Making it Work approach)
- Coordination work to produce an alternative report to be sent to the Committee on the Rights of Persons with Disabilities

Examples of indicators:

- An alternative report is produced in consultation with a wide-range coalition of actors and submitted to the Committee on the Rights of Persons with Disabilities in due course of time (covering all rights for all persons with disabilities)
- Reports on the situation of persons with disabilities are produced, disseminated to key stakeholders and made available in accessible formats
- By XX, DPOs have produced XX rights monitoring reports (e.g. one each year) on access to health, education, livelihood services, etc. and disseminated them to media, ministries, NGOs, INGOs
- Clear recommendations for legislation review are formulated by DPOs based on comparative review
- A multi-stakeholder Making It Work report on good practices is produced identifying key recommendations to implement Article XX of the UNCRPD at local/ national/ regional level(s)

Component 4 - Support the individual empowerment of persons with disabilities

Working with DPOs is a way to address challenges faced by persons with disabilities at the collective level. This document recalls on many occasions the need to ensure that collective action (speaking and advocating on behalf of members, influencing policy change and perceptions of the general public) should be oriented on the goal of achieving positive impact on the lives of persons with disabilities.

Developing good governance of DPOs is a way to ensure that information and resources circulate widely within the organisation and do not only benefit to a few members. Similarly, the bottom-up approach proposed by Making It Work aims to ensure that practices that work and have demonstrated their impact in enhancing participation of persons with disabilities can be disseminated and replicated on a broader scale.

Component 4 is yet another way to insist on this essential connection and the individuals they aim to represent. DPOs need to work for themselves as organisations to achieve goals through collective action, but also need to remain focused by the situation of their individual members. Several pathways are proposed in this chapter.

A

Engage in service delivery

Support to individuals with disabilities is an essential way for a DPO to understand the situation of its members and to generate evidence for advocacy activities. Moreover, **DPOs are often the first place for individuals to turn when seeking support or help.** This individual support is a key component of a DPOs' activities and a key action for reinforcing its legitimacy. If members of DPOs see concrete benefits, this will most likely increase the membership and make these organisations stronger and more credible. Taking this into consideration, the mission of a DPO should always be a balancing act between advocacy work and providing individual support; indeed these are two ways for the effective implementation of the rights of persons with disabilities.

Controversy and debate exists around the pertinence of DPOs' involvement in service delivery. There are a range of different attitudes and perceptions on this issue, depending on the context and circumstances (in France for example, DPOs and parents' association in particular have a major part in the provision of services to persons with disabilities). HI acknowledges this, and has been working with DPOs as representatives of persons with disabilities/ users, as service providers, or as both. In this case, **there needs to be a clear distinction between the roles of service providers and representatives of users of services in order to avoid conflicts of interest⁶⁰.**

Federations of DPOs which have this special mandate to speak with national authorities on behalf of persons with disabilities should prevent from engaging in service delivery for this very reason. This is less of a concern for other DPOs who can be both involved in service delivery and channel their advocacy through the national federation. Practices in many countries over recent decades tend

to demonstrate that DPOs should not try to manage services for which professional expertise is needed (e.g. a rehabilitation centre) especially if such expertise is available in-country. When it comes to individual support, DPOs should instead invest more into areas where they have an added value that others don't have. For example, Braille or Sign Language training is often organized by associations of people with visual or hearing impairment. However, one should remain open and flexible as the situation will depend on the context and choices of DPOs.

B

Contribute to members' empowerment

The purpose of support to individuals carried out by DPOs is the empowerment and personal growth of the person. Persons with disabilities should be enabled to live a decent life and become active members of their community. Due to stigma and marginalization, persons with disabilities often lack confidence to interact with others and engage in community activities. For individuals who have been cared for by others (institutionalized or dependent on family support), it is sometimes overwhelming to be confronted with decision-making and personal choices. As such, despite having rights and obligations as citizens, persons with disabilities are not always well equipped to act on them.

Through peer counselling⁶¹, training on rights and self-advocacy, or the provision of space for discussion and experience sharing, DPOs can help their members to develop self-esteem. Active involvement with others in awareness and advocacy campaigns can be another way for persons with disabilities to gain confidence and challenge negative self-image. The experiences and achievements of fellow members is often the best motivation for moving forward and taking up challenges. This is of particular interest for issues such as management of personal assistance, self-determination and independent living etc.

Component 4 - Support the individual empowerment of persons with disabilities

C

Serve as an information and orientation platform

DPOs are often the first place where individuals turn for support and help. This is especially the case in countries where social services are either non-existent or poorly developed. Hence DPOs need to be prepared to address the various requests of their visitors. This means structuring relevant information and contacts so they will be able to orient individuals more efficiently. Handicap International has been supporting **DPOs** technically and financially **to build their capacities and function as providers of referral and information support** on questions as diverse as health, rehabilitation, education, citizenship, accessibility, managing a relationship with a personal assistant, etc..



Focus - Example of a DPO involved in information and referral: 'Centre local d'information et d'orientation pour les personnes handicapées' (CLIO) in Morocco

The Local Centre for Information and Orientation (CLIO) is a local level information, guidance and referral centre in support to persons with disabilities and their relatives. Managed by the Disabled People Club (DPO of 750 members) of Bouregreg Association, it aims to strengthen participation of persons with disabilities in society through improving their access to services.

An initiative within a broader inclusive development approach at the local level, the CLIO addresses requests from persons with disabilities (more than 2,000 people per year) and helps them to identify and access relevant services according to their needs and priorities. The CLIO strongly relies on building networks with existing mainstream and disability-specific services at the local level. A key component of its success lies with complementary awareness activities aimed at changing attitudes towards disability and mobilizing local actors to welcome and provide support to persons with disabilities on an equal basis with others.

Having started in the district of Tabriquet, it has expanded to cover the 4 districts of Salé City and the whole Bouregreg river mouth area. The CLIO is now seen as a network of local solidarities where persons with disabilities feel welcome and supported by their community. The innovative aspect of this simple and straightforward set-up is now taken as an example to inspire a nation-wide policy for access of persons with disabilities to services in Morocco.



Focus - 'Light group for People with Visual Impairment and Persons with disabilities' in Egypt

In developing countries, the majority of requests of persons with disabilities are related to services and access to services. DPOs can facilitate this access by **developing directories of existing services**, including practical information for persons with disabilities on issues such as accessibility.

Working in close cooperation with DPOs and service providers, HI Nepal, for example, has developed a practical guide for referral and a directory of specialist services covering the whole country. In Mozambique, HI and its partner DPO (RAVIM) have produced a directory of all (mainstream and specialist) services and assessed their accessibility for persons with disabilities in the capital city of Maputo-Matola.

HI can support DPOs to develop their skills as councillors who are well informed and able to mobilize community resources and services, knowing how to assess their quality and the accessibility for persons with disabilities.

Provide administrative support and guidance

DPOs can be of great support for ensuring their members benefit from specific provisions for persons with disabilities (where they exist) and other citizenship services. For example when obtaining a disability identification card, a voter's card, citizenship or birth certificate, or getting the benefits that are linked to these documents, such as financial compensation, discounts on public transportation etc.

Through the micro-grants scheme of the Musawa project, HI has supported an initiative from a DPO called "Light group for the blind and Persons with disabilities". The local initiative coming from Qena-Egypt is raising the awareness of persons with disabilities about their own rights. The main objective is to increase the awareness of persons with disabilities about their right to participate in elections, their right to be integrated in the political life of their community and the right to express their views. The DPO supports them to obtain voter cards and with the ongoing democratisation process in Egypt, this need for persons with disabilities to express their opinion and to participate in elections is felt even more strongly.

Component 4 - Support the individual empowerment of persons with disabilities

Development of a 'Directory on rights of persons with disabilities' in Nepal

In Nepal, HI supported the development of a 'Directory on rights of persons with disabilities'. The rationale for this has been the observation that few persons with disabilities in Nepal know about their rights, are familiar with the laws existing or have access to stakeholders that could provide support and assistance.

The handbook presents guidelines on existing provisions, facilities and rights in Nepal, in line with the UNCRPD. The brochure contains valid information focusing on the individual person with a disability, (e. g. how to get an ID card and what are the benefits) and also offers contacts for DPOs, and contacts for legal aid organisations and human rights observers if rights are denied.

Furthermore, the handbook offers tools and knowledge for the district and national level and for legal experts and human rights advocates on how to advocate and protect the rights of persons with disabilities. Good practice stories complete this very useful guide for the empowerment of persons with disabilities.

DPOs occasionally play a role in legal support to individual persons with disabilities. This work requires specific skills to navigate the judiciary system and can be quite costly. HI, favouring mediation, does not usually engage with DPOs in this type of work, but rather supports them to make relevant referrals.



- Summary of Project Component 4 -

Objective: Support the individual empowerment of persons with disabilities

Examples of Expected Results:

- Persons with disabilities develop their autonomy, confidence, skills and capacities through support provided by DPOs
- DPOs advise the development of relevant services for persons with disabilities and facilitate access to these services

Examples of activities:

- Setting-up of a Local Centre for Information and Orientation (CLIO) for persons with disabilities
- IEC material with simple explanations on rights and benefits and how to get them
- Referral for legal support
- Providing targeted support to increase autonomy/ promote self-determined living
- Information and orientation services
- Independent living centres
- Training and support to develop persons with disabilities' self-esteem and confidence
- Leadership and self-advocacy training
- Peer group counselling
- Sign language training
- Organise self-help groups
- Support to persons with disabilities for citizenship, disability card, registration, administrative work to obtain disability allowance etc
- Advise development of services for persons with disabilities (rehab centres...)
- One-off targeted interventions in answer to micro-projects (call)

Examples of indicators:

- DPOs give support to persons with disabilities for self-determination and autonomy: no. of counselling sessions and trainings, reports , feed-back / evaluation of participants
- DPOs organise XX self-help groups, e.g. women with disabilities in communities, that take over responsibilities themselves at a certain point: reports, list or minutes of meeting
- DPOs facilitate access to services: reports,

evaluation of users' opinion

- The level of satisfaction of persons with disabilities has increased from XX % to XX% (baseline studies required) for services rendered
- persons with disabilities in XX district/ province and families are informed and aware of their rights: reports
- DPOs provide practical support to persons with disabilities for self-determination and advocacy: nb. of counselling sessions and trainings, reports , feed-back / evaluation of participants
- DPOs advise development of relevant services for persons with disabilities and facilitate access to these services: advisory documents, minutes of meetings with representatives concerned
- DPOs have implemented XX community-based "innovative projects" that protect and promote the rights of persons with disabilities : project reports and evaluations
- XX Persons with disabilities have quick access to legal service providers: reports, baseline study
- XX Persons with disabilities who are victims of sexual violence have quick access to legal, health and psychosocial services: reports, baseline study
- XX PwD have a birth certificate as the result of this project: reports, baseline study
- DPOs have set up at least XX inclusive projects in the locality/district/province: project reports and evaluations

End of Intervention Methods



Mali, 2010

Appendices

Glossary	70
List of Acronyms	75
Reference documents and resources	76
Major actors and websites	80
List of projects analysed	84
Footnotes	86

ADVOCACY

Advocacy is a communication process through which individuals, groups or communities influence policy makers and opinion formers to bring about changes to policy and practice. Advocacy covers a broad range of activities, from awareness-raising to lobbying to influence specific legislation. In the development context, advocacy is generally understood as a process that aims to bring about change in process, policy or practice, so that structural causes of poverty and disadvantage are reduced. Advocacy is about achieving equity and social justice through the empowerment of disadvantaged people so that they participate more directly in decisions that affect their lives. For advocacy to be taken seriously, it needs to be based on evidence and be conducted by those who are concerned by the situation to be changed. Actions need to be planned strategically and need to be adapted according to the intended audience, expected change, political agenda, evolving opportunities, expected support from other groups, etc.

AWARENESS-RAISING

Awareness-raising is about bringing an issue to the knowledge of a person or a group. It strives to address attitudes, social relationships and power relations to effect social change and as such, can be part of an advocacy strategy. However, it is often only a first step towards changing practices. Awareness-raising on the situation of persons with disabilities can, for example, help a decision-maker to realise that there is a significant proportion of persons with disabilities in the community that s/he administers; but it won't be sufficient to ensure that priorities of persons with disabilities issues are systematically included in community development planning.

Awareness-raising can be conducted using a variety of mediums and tools selected according to the type of audience, such as street theatre, posters, interactive sessions, etc. Awareness activities on disability should never be planned without close consultation with, and involvement of, persons with disabilities themselves or their representative organisations.

CAPACITY DEVELOPMENT

Capacity development is an organic process that helps a person, group or organisation to evolve. It involves individual and organisational learning for building social capital and trust, developing knowledge, skills and attitudes and creating an organisational culture that will enable organisations to set objectives, achieve results, solve problems and create adaptive procedures for ensuring their long-term survival⁶².

Capacity: the ability of people, organisations and society as a whole to manage their affairs successfully (RESULT).

Capacity development: the process whereby people, organisations and society as a whole, strengthen, create, adapt and maintain capacity over time (PROCESS).

Support to capacity development: what outside partners (domestic or foreign) can do to support, facilitate or catalyse capacity development and related change processes (INPUT)⁶³.

DISCRIMINATION and NON-DISCRIMINATION

Non-discrimination is a fundamental principle of international human rights law. As a human rights treaty, the purpose of the UNCRPD is essentially the protection of persons with disabilities against discrimination: in this perspective, the UNCRPD does not create new rights but identifies specific actions that States must take to protect against discrimination on the basis of disability.

Discrimination on the basis of disability is defined in Article 2 of the UNCRPD. It “means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation”.

Hence the UNCRPD protects against direct discrimination (for example, if a child is denied access to school on the basis of his/her disability) and against indirect discrimination (measures that appear not to make any distinction but end up in discriminating, for example organizing a meeting on the second floor of a building without a lift). The principle of non-discrimination does not prevent targeting specific groups of vulnerable people. Rather than discrimination, this should be considered as affirmative action to address immediate or priority needs.

EMPOWERMENT

Empowerment is the process of increasing the capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes.

Central to this process are actions which both build individual and collective assets, and improve the efficiency and fairness of the organisational and institutional context which govern the use of these assets.⁶⁴

Empowerment is the expansion of assets and capabilities of marginalised people to participate in, negotiate with, influence, control, and hold accountable institutions that affect their lives. Since poverty is multidimensional, poor people need a range of assets and capabilities at the individual level (such as health, education, and housing) and at the collective level (such as the ability to organise and mobilize to take collective action to solve their problems)⁶⁵.

HUMAN RIGHTS BASED APPROACH TO DEVELOPMENT⁶⁶

The Human-Rights Based Approach to Development consists of applying a ‘human rights lens’ to development. It was developed by the UN and entails five key notions:

1. A systematic reference to human rights (realisation of human rights as the objective, covering all rights as they are indivisible and interdependent, in all sectors)
2. Accountability (of duty-bearers including the State, policy-makers, professionals, parents... towards right-holders, i.e. in our case persons with disabilities)
3. Empowerment and development of capacities is considered as a goal
4. Participation is the main methodology
5. Non-discrimination and attention to vulnerable groups (paying specific attention to the most vulnerable and marginalised)

This approach has by now been incorporated into the policies, programming and working methods of the vast majority of international development actors, as a way

to bridge the gap between human rights and development, which for too long had evolved in separate spheres. Since its creation in 1982, Handicap International has always actively promoted the human rights of persons with disabilities, recognising this as a key reference point for defining interventions. However Handicap International's programming is not specifically guided by the five pillars outlined above, but by a broader set of tools and approaches derived from practical experience over many years.

HUMAN RIGHTS APPROACH TO DISABILITY

The human rights approach to disability consists of recognising that persons with disabilities are entitled to enjoy the same rights as others, and that these rights need to be promoted for their full participation in society.

"The goal of a human rights approach to disability is to ensure the equal dignity and equal effective enjoyment of all human rights by persons with disabilities. What are referred to as disability rights and the human rights of persons with disabilities are not extra protections or a separate and special category of rights, but part of the full range of human rights available to everyone. All people have the right to participate and to exercise self-determination as equals in society"⁶⁷.

The human rights approach to disability uses the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD) as a major tool and reference to advance the rights of persons with disabilities. Having been directly involved in the elaboration process of the UNCRPD, Handicap International endorses this approach and our programmes throughout the world continue to support effective implementation of the UNCRPD.

INCLUSIVE DEVELOPMENT

Inclusive Development is the design and effective implementation of public policies and actions that bring about socio-economic and human development, in a way that promotes the capacities and equal opportunities and rights of all people, regardless of their social condition, gender, age, disability, ethnicity, religion, sexual orientation, etc.⁶⁸

Inclusive development, as defined here, refers to ensuring that all phases of the development cycle (design, implementation, monitoring and evaluation) include a disability dimension and that persons with disabilities are meaningfully participating in development processes and policies.

Inclusive development:

- (i) ensures that persons with disabilities are recognised as rights-holding equal members of society who must be actively engaged in the development process irrespective of their disability or other status such as age, sex, race, ethnicity, religion or other status; and
- (ii) that development institutions, policies and programmes must take into account and be assessed in accordance with their impact on the lives of persons with disabilities, and consistent with the promotion and protection of internationally recognised human rights⁶⁹

Inclusive development is a rights-based process that promotes equality and the participation of the largest possible section of society, especially groups that face discrimination and exclusion. Inclusive development ensures that persons with disabilities are recognised as rights-holding equal members of society, who are engaged and contributing to a development process for all. Inclusive development can be implemented at national and at local level⁷⁰.

INDEPENDENT LIVING

Independent living is a philosophy and a global movement that advocates for the right of persons with disabilities to live in a community, and their right to self-determination and is based on the premise that even people with the most severe disabilities should have the choice of living in the community. Living independently means a person with a disability living in the community, with appropriate support, so that s/he may live with dignity and make personal life decisions to the best of her/his ability. Support for the right of all people to live as independently as possible is integral to the process of deinstitutionalisation of people with intellectual disabilities⁷¹. The concept of independent living makes clear that persons with disabilities are not expected to live without support. It does not mean persons with disabilities 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations.

LOBBYING

Lobbying is a subset of advocacy that aims to influence specific legislation. Advocacy covers a much broader range of activities which might, or might not, include lobbying. Almost all social change has started with non-lobbying advocacy but ended with major lobbying efforts. Examples: the protection of women's rights, child labour laws: all initially combined a broad spectrum of non-lobbying advocacy activities, with lobbying employed somewhat later to achieve the needed change.

PEER COUNSELLING and PEER SUPPORT

"Peer counselling is a particular form of counselling, based on the experience of associations and of persons with disability, to favour an individual empowerment process and consequently one of social emancipation."

"Peer support is a service offered inside the informative organisations that deal with specific problems regarding target groups that live a condition of social disadvantage. The group of persons with disability is one of these groups. The peer support service is characterised by a relationship between 'peers'. (...) The condition of equality facilitates the help-relationship, in as far as the peer supporter avails himself not only of the technical competences acquired on a theoretical level, but also of his life experience, favouring in this way a better comprehension and communication of problems between the individuals that interact. (...)The peer support activity is useful to activate cultural, informative and political campaigns that aim at the improvement of the quality of life of all subjects, or of a certain specific part of the population, by obtaining services, structures, laws, etc. tailored to their needs"⁷².

PARTICIPATION OF PERSONS WITH DISABILITIES

The "full and effective participation and inclusion [of persons with disabilities] in society" is one of the general principles of the UNCRPD. Participation can be understood as both a goal and a process:

- A goal: the situation of social participation⁷³ is the opposite of the situation of disability. According to the social model, situations of disability can disappear once all barriers to equal participation are removed.

- A process: participation of persons with disabilities can only be achieved through the active involvement of persons with disabilities in decision-making and actions that affect their lives. Article 4.3 of the UNCRPD creates an obligation to “closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations” for any “decision-making processes concerning issues relating to persons with disabilities”.

POLICIES, SYSTEMS, SERVICES

Policies - The rules, regulations and standards established by local, regional, national and international government or other recognised authorities, which govern or regulate systems that control services, programmes and other infrastructural activities in various sectors of society

Systems - The administrative control and organisational mechanisms established by governments at the local, regional, national, and international levels, or by other recognised authorities. These systems are designed to organise, control and monitor services that provide benefits, structured programmes and operations in various sectors of society.

Services - The provision of benefits, structured programmes and operations, which may be public, private or voluntary, and established at a local, community, regional, state, provincial, national or international level by employers, associations, organisations, agencies or government in order to meet the needs of individuals (including the persons who provide these services). The goods provided by a service may be either general or adapted and specially designed.⁷⁴



List of Acronyms

COSP	Conference of the State Parties (to the UNCRPD)
DCP	Disability Creation Process
DECISIPH	Droits, Egalité, Citoyenneté, Solidarité, Inclusion des Personnes Handicapées
DPO	Disabled People's Organisation
HI	Handicap International
ICF	International Classification of Functioning, Disability and Health
IDA	International Disability Alliance
IDDC	International Disability and Development Consortium
ILD	Inclusive Local Development
MIW	Making it Work
OHCHR	Office of the High Commissioner for Human Rights
SHARE-SEE	Self-Help and Advocacy for Rights and Equal Opportunities South East Europe
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDESA	United Nations Department of Economic and Social Affairs



Reference documents and resources

Main resources

- HANDICAP INTERNATIONAL, **SKILL Web:** Handicap International technical resources website: <http://www.hiproweb.org/fr/accueil/accueil.html>
- HANDICAP INTERNATIONAL, **Disability Rights and Policies: Reference Documents and Resources**, Jan. 2008. This cd-rom, also available online (<http://www.handicap-international.fr/bibliographie-handicap/>) includes numerous resources including on: disability, human rights, disability policies, civil society (DPOs), actors and networks.
- HANDICAP INTERNATIONAL, **Making it Work;** Making it Work website includes a good practices database on implementation of articles of the UNCRPD, and a library of relevant resources: <http://www.makingitwork-crpd.org/informationlibrary/>
- HANDICAP INTERNATIONAL, **SOURCE;** International Information Support Center, www.asksource.info

Disability, development and human rights

- HANDICAP INTERNATIONAL, **UN Convention on the Rights of Persons with Disabilities: Training Kit**, 2007. <http://www.handicap-international.fr/kit-pedagogique/indexen.html>
- HANDICAP INTERNATIONAL / Marianne Schultze, **Understanding the UN Convention on the Rights of Persons with Disabilities, A handbook on the Human Rights of Persons with Disabilities**, July 2010 http://www.makingitwork-crpd.org/fileadmin/user/CRPD_Resources/HICRPDManual.pdf
- HANDICAP INTERNATIONAL, **Understanding disability: look, then act**, Interactif n°10, Décembre 2002 <http://www.handicap-international.fr/bibliographie-handicap/1Handicap/FrameUS.htm>
- DE RIEDMATTEN Raphaël (sous la dir. de). **Une nouvelle approche de la différence : comment repenser le handicap.** Genève : Editions Médecine et Hygiène, 2002. <http://www.handicap-international.fr/bibliographie-handicap/1Handicap/FrameUS.htm>
- ALBERT, Bill, **In or out of the mainstream? Lessons from research on disability and development cooperation**, The Disability Press Leeds, 2006
- WHO, World Bank, **World Disability Report**, 2011. http://www.who.int/disabilities/world_report/2011/report/en/index.html

Capacity development

- HANDICAP INTERNATIONAL, **Capacity Development: Reference Documents and Resources**, June 2010. http://www.hiproweb.org/fileadmin/cdroms/Biblio_Renforcement/index.html
- HANDICAP INTERNATIONAL / Stefanie Ziegler, **Capacity Development and Partnership: Overview and Methodology**, 2008
http://drt.handicap-international.fr/uploads/tx_hidrtdocs/RenfCapEng.pdf
- World Neighbours / Peter Gubbels, Cathryn Koss
From the Roots Up, Strengthening Organisational Capacity through guided Self Assessment, World Neighbours Field Guide, USA, 2000
http://www.hiproweb.org/fileadmin/cdroms/Biblio_Renforcement/English/contenu3.htm
- HANDICAP INTERNATIONAL / Delphine Pastiaux-Murphy
Partenariat et renforcement organisationnel de structures locales de développement : éléments d'analyse et de stratégie, Addis Abeba, 2004
http://www.hiproweb.org/fileadmin/cdroms/Biblio_Renforcement/English/contenu4.htm
- HANDICAP INTERNATIONAL / Philippe Villeval
Towards a policy framework for the empowerment of a social movement, 2006
- HANDICAP INTERNATIONAL / Alana Officer
Organisational Capacity Assessment Tool, Delhi, 2003
http://www.hiproweb.org/fileadmin/cdroms/Biblio_Renforcement/English/contenu3.htm
- International HIV / AIDS Alliance
CBO Capacity Analysis: A toolkit for assessing and building capacities for high quality responses to HIV, Brighton, 2007
http://www.hiproweb.org/fileadmin/cdroms/Biblio_Renforcement/English/contenu3.htm
- International HIV / AIDS Alliance
NGO Capacity Analysis: A toolkit for assessing and building capacities for high quality responses to HIV/AIDS, Brighton, 2004
http://www.hiproweb.org/fileadmin/cdroms/Biblio_Renforcement/English/contenu3.htm
- INTRAC / Rick James, John Hailey
Capacity Building for NGOs - Making It Work, Praxis Series n°2, Oxford, 2007
http://www.hiproweb.org/fileadmin/cdroms/Biblio_Renforcement/English/contenu2.htm
- INTRAC / Rick James, **Just Do It: Dealing with the Dilemmas in Monitoring and Evaluation of Capacity Building**, Praxis Note n°49, Oxford, 2009
http://www.hiproweb.org/fileadmin/cdroms/Biblio_Renforcement/English/contenu2.htm
- HANDICAP INTERNATIONAL / N. Heeren, B. Crishna
Work on Participatory Programming, Participatory Evaluation, How are we doing? Participatory evaluation in the practice of Handicap International, 2001
- BARBUTO R., FERRARESE V. GRIFFO G., NAPOLETANO E., SPINUSO G., **Peer counselling (from victims of the history to protagonists of life)"**, Lamezia Terem (Italy), Comunità Edizioni, 2006.

APPROACHES AND TOOLS FOR ADVOCACY

- Office of the High Commissioner for Human Rights (OHCHR), **Convention on the Rights of Persons with Disabilities, Advocacy Toolkit**, July 2008
http://www2.ohchr.org/english/issues/disability/docs/CRPD_Advocacy_Tool.pdf
- European Coalition for Community Living (ECCL), **Creating successful campaigns for community living, an advocacy manual for disability organisations and service providers**, Nov. 2008
<http://www.community-living.info/documents/ECCL-Manual-final-WEB.pdf>
- Human Rights Resource Centre / Janet E. Lord, Katherine N. Guernsey, Joelle M. Balfe, Valerie L. Karr, **Human Rights, YES! Action and Advocacy on the Rights of Persons with Disabilities**, Nancy Flowers Editions
<http://www1.umn.edu/humanrts/edumat/hreduseries/TB6/>
- FIORAMONTI Lorenzo, HEINRICH V. Finn, **How Civil Society Influences Policy: A Comparative Analysis of the CIVICUS Civil Society Index in Post-Communist Europe**, 2007.- 56 p.
http://www.civicus.org/new/media/CIVICUS_ODI.Fioramonti.Heinrich.pdf
- Overseas Development Institute (ODI), POLLARD Amy, COURT Julius. **How Civil Society Organisations Use Evidence to Influence Policy Processes: A literature review**, London : ODI, 2005. - 39 p.
<http://www.odi.org.uk/resources/download/140.pdf>
- Overseas Development Institute (ODI), RAPID, J. Court, E. Mendizabal, D. Osborne and J. Young, **Policy Engagement: How Civil Society Can be More Effective**, London : ODI, 2006. - 60 p.
<http://www.odi.org.uk/resources/download/160.pdf>
- CARE / Sofia Sprechmann, Emily Pelton. **Outils et Directives pour le Plaidoyer: Promouvoir le Changement des Politiques :** Atlanta : Care, 2001
<http://www.handicap-international.fr/bibliographie-handicap/6SocieteCivile/Advocacy/CAREFre.pdf>
- CARE / Sofia Sprechmann, Emily Pelton, **Advocacy Tools and Guidelines: Promoting Policy Change**, Atlanta : Care, 2001.
<http://www.handicap-international.fr/bibliographie-handicap/6SocieteCivile/Advocacy/CAREEng.pdf>
- INTRAC/ John Beuclerk, Brian Pratt and Ruth Judge, **Civil Society in Action: Global Case Studies in a practice-based framework**, 2011.



HUMAN RIGHTS & POLICY monitoring

- International Disability Alliance (IDA), **Guidance Document on the effective use of international human rights monitoring mechanisms to protect the rights of persons with disabilities**, May 2010 - available in English, Spanish, French and Arabic:
<http://www.internationaldisabilityalliance.org/projects-and-events/guidance-document-on-parallel-reporting/>
- Office of the High Commissioner for Human Rights (OHCHR), **From Exclusion to Equality, Realising the Rights of Persons with Disabilities, a Handbook for Parliamentarians**, 2007
<http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf>
- Office of the High Commissioner for Human Rights (OHCHR), **Monitoring the UNCRPD, Guidance for Human Rights Monitors**, http://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf
- CAFOD / ChristianAid, TRoCAIRE: **Monitoring Government Policies, a toolkit for civil society organisations in Africa**
<http://cdg.lathyrus.co.uk/docs/MonitorGovPol.pdf>
- Disability Rights Promotion International (DRPI), **Moving forward, Progress in global disability rights monitoring**, 2007
<http://www.yorku.ca/drpi/files/MovingForwardFINAL.pdf>
- Disability Rights Promotion International (DRPI), **Opportunities, Methodologies and Training Resources for Disability Rights Monitoring**, 2003
http://www.yorku.ca/drpi/files/DRPI_Phase_I_Report.pdf
- Anna Lawson, Mark Priestley, **Monitoring the Implementation of the UN Convention on the Rights of Persons with Disabilities in Europe: Principles for the Identification and Use of Indicators**, University of Leeds, May 2009
<http://www.disability-europe.net/theme/monitoring-rights>
- Office of the High Commissioner for Human Rights (OHCHR), **Working with the United Nations Human Rights Programme**, 2008
http://www.ohchr.org/EN/AboutUs/CivilSociety/Documents/Handbook_en.pdf

Major actors and websites

INTERNATIONAL DISABILITY ALLIANCE (IDA)

Established in 1999, the International Disability Alliance (IDA) is **a network of global and regional organisations of persons with disabilities (DPOs) promoting the effective implementation of the UN Convention on the Rights of Persons with Disabilities**. IDA currently comprises eight global and four regional DPOs, with two other regional DPOs having observer status. With member organisations around the world, IDA represents the estimated 650 million people worldwide living with a disability. This is the world's largest - and most frequently overlooked - minority group.

Among other activities, IDA is the key focal point for the disability rights movement in developing an ongoing relationship between the UN organs and civil society, including DESA, the OHCHR, the Conference of States Parties, special procedures, and most recently, the CRPD Committee. IDA is also committed to building the capacity of national DPOs with special attention to the Global South, in order to support the national efforts toward ratification, implementation and monitoring of the CRPD. The IDA website entails relevant resources on advocacy work as well as DPO capacity development: <http://www.internationaldisabilityalliance.org/>

IDA members:

- Disabled Peoples' International (DPI): <http://www.dpi.org/>
- Down Syndrome International (DSI): <http://www.ds-int.org/>
- Inclusion International (II): <http://www.inclusion-international.org/>
- International Federation of Hard of Hearing People (IFHOH): <http://www.ifhoh.org>
- World Blind Union (WBU): <http://www.worldblindunion.org/en/>

- World Federation of the Deaf (WFD): <http://www.wfdeaf.org/>
- World Federation of Deafblind (WFDB): <http://www.wfdb.org/>
- World Network of Users and Survivors of Psychiatry (WNUSP): <http://www.wnusp.net/>
- Arab Organisation of Disabled People (AODP)
- European Disability Forum (EDF): <http://www.edf-feph.org/>
- Latin American Network of NGOs of Persons with Disabilities and their families (RIADIS): <http://www.riadis.net/>
- Pacific Disability Forum: <http://www.pacificdisability.org/>

SECRETARIAT FOR THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The Convention on the Rights of Persons with Disabilities and its Optional Protocol are serviced by a **joint Secretariat**, consisting of staff of both the United Nations Department of Economic and Social Affairs (DESA), based in New York, and the Office of the High Commissioner for Human Rights (OHCHR) in Geneva.

The mandates of the Secretariat for the Convention on the Rights of Persons with Disabilities include the Convention on the Rights of Persons with Disabilities adopted in 2006, the Standard Rules on Equalization of Opportunities for Persons with Disabilities adopted in 1994, and the World Programme of Action Concerning Disabled Persons adopted in 1982.

In addition, the Secretariat prepares publications and acts as a clearinghouse for information on disability issues; promotes national, regional and international programmes and activities; provides support to governments and civil society; and gives substantial support to technical co-

operation projects and activities.
<http://www.un.org/disabilities/default.asp?id=150>

UNITED NATIONS DEPARTMENT OF ECONOMIC AND SOCIAL AFFAIRS (UNDESA)

The mission of the UNDESA is to promote development for all, with a fundamental concern for equity and equality in countries large and small, developed and developing. UNDESA works on issues ranging from poverty reduction, population, gender equality and indigenous rights to macroeconomic policy, development finance, public sector innovation, forest policy, climate change and sustainable development. The Department also supports the effort to achieve the Millennium Development Goals.

The UNDESA is **one of the agencies serving as Secretariat to the UNCRPD** (together with OHCHR in Geneva). The UNDESA **services the Conference of States Parties (COSP) to the Convention** that convenes in New York (while OHCHR services the Committee on the Rights of Persons with Disabilities that meets in Geneva).

The objectives of the Secretariat at DESA are: (i) to support the full and effective participation of persons with disabilities in social life and development; (ii) to advance the rights and protect the dignity of persons with disabilities and; (iii) to promote equal access to employment, education, information, goods and services. The mandate of the Secretariat at DESA also includes the review and implementation of the Standard Rules on Equalization of Opportunities for Persons with Disabilities adopted in 1994, and the World Programme of Action Concerning Disabled Persons adopted in 1982.

<http://www.un.org/esa/desa>

OFFICE OF THE HIGH COMMISSIONER FOR HUMAN RIGHTS (OHCHR)

The High Commissioner for Human Rights is the principal human rights official of the United Nations. The Office of the High Commissioner for Human Rights (OHCHR) is part of the United Nations Secretariat with its headquarters in Geneva. Its mandate is to promote and protect all human rights.

OHCHR is one of the agencies serving as **Secretariat to the UNCRPD** (together with UNDESA in New York). The OHCHR **services the Committee on the Rights of Persons with Disabilities** that meets in Geneva (while the UNDESA services the Conference of States Parties (COSP) to the Convention that convenes in New York).

The objectives of the Secretariat at OHCHR, drawn from the High Commissioner's Plan of Action, are: (i) country engagement - to support UN human rights field presences increase their work at the country level on the Convention, with a particular focus on awareness-raising and promoting ratification; (ii) support for human rights bodies - to mainstream disability within the UN human rights programme, specifically in the work of the Human Rights Council and the existing treaty monitoring bodies; (iii) leadership - to encourage the High Commissioner to raise awareness of disability as a human rights issue and to provide tools and publications to assist States, civil society organisations and national human rights institutions to implement the Convention; and, (iv) partnership - to work closely with other intergovernmental and civil society organisations to strengthen work on the Convention through cooperation.

<http://www.ohchr.org/EN/Pages/WelcomePage.aspx>

COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

The Committee on the Rights of Persons with Disabilities (CRPD) is the **body of independent experts which monitors implementation of the UNCRPD by the States Parties**. All States parties are obliged to submit regular reports to the Committee on how the rights are being implemented. States must report initially within two years of accepting the Convention and thereafter every four years. The Committee examines each report and shall make such suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the State Party concerned. The Committee meets in Geneva and normally holds two sessions per year.
<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>

DISABILITY RIGHTS PROMOTION INTERNATIONAL (DRPI)

Disability Rights Promotion International (DRPI) is a collaborative project working to establish a **monitoring system to address disability discrimination globally**. DRPI has adopted a holistic approach to disability rights monitoring, with three focus areas: individual experiences monitoring, systemic monitoring and media monitoring. The DRPI website entails country-specific as well as general resources on disability rights monitoring: <http://www.yorku.ca/drpi/resources.html>

INTERNATIONAL DISABILITY AND DEVELOPMENT CONSORTIUM (IDDC)

The International Disability and Development Consortium is a global consortium of 23 disability and development non-governmental organisations (NGOs),

mainstream development NGOs and disabled people's organisations (DPOs) supporting disability and development work in more than 100 countries around the world. The **aim** of IDDC is to promote inclusive development internationally, with a special focus on promoting the full and effective enjoyment of human rights by all disabled people living in economically poor communities in lower and middle-income countries.

Resources can be found on the IDDC website: <http://www.iddcconsortium.net/joomla/index.php/home> as well as on the website of the IDDC project 'Make Development Inclusive': <http://www.make-development-inclusive.org/>

MAKING IT WORK

Making it Work is a global, multi-stakeholder initiative to promote effective implementation of the CRPD.

In all countries of the world there are many examples of innovative projects and good practices that have achieved real impact in addressing the exclusion and discrimination experienced by people with disabilities. Understanding these good practices (how they were achieved, how they apply to specific contexts and how they can be replicated or scaled-up) is essential to the effective implementation of the Convention on the Rights of Persons with Disabilities ~ i.e. to making the CRPD work!

Making it Work is a methodology for researching and documenting good practices on key disability issues, and then using this evidence to carry out effective advocacy. The methodology is straightforward: it can be used to develop projects on any disability issue, in any country, at any level, by all types of organizations. Indeed many organizations throughout the world are now using this approach. The Making it Work website offers a platform

to share their good practice research and recommendations. Please visit: www.makingitwork-crpd.org to find essential information about Making it Work and to download the Making it Work Guideline.

INTERNATIONAL DISABILITY RIGHTS MONITOR

The International Disability Rights Monitor (IDRM) is an international grassroots research project aimed at producing series of regional reports on disability and human rights, sometimes with a thematic focus. Reports are available on the IDRM website: <http://www.idrmnet.org/index.cfm?m=1>

OTHER RELEVANT WEBSITES

- **Disability Awareness in Action:** <http://www.daa.org.uk/>
- **International Disability and Development Consortium (IDDC):** <http://www.iddcconsortium.net>
- **Global Partnership on Disability and Development:** <http://www.gpdd-online.org/>



List of projects analysed⁷⁵

Afghanistan	Capacity Building of an Afghan NGO for the Social and Economic Inclusion of Persons with Disabilities in Afghanistan; Community Centre for the Disabled: A resource centre for persons with disabilities
Angola	Moving Towards an Inclusive Society - Strengthening disabled people's voices in Angola
Bangladesh	Set up a partnership between Abilis Foundation (Finland) and Handicap International (Bangladesh)
Bangladesh	Promoting the Rights of Persons with Disabilities in Bangladesh
Burkina Faso and Niger	Improving the participation of citizens in a disabling situation in Burkina Faso and in Niger for the recognition of their rights through the strengthening of their organisations
Cambodia	Promoting the rights and inclusion of persons with disabilities in Cambodia
Cambodia	Mainstreaming disability in Cambodian Development Policies: Promoting the right of inclusion with Disabled People's Organisations.
Central America (Nicaragua, Guatemala, Colombia, El Salvador)	Central America accessible and inclusive for people with disability
China (Tibet)	Support to the Tibet Deaf Association - Tibet Autonomous Region - China
Ethiopia	Legal Rights of empowerment of people with disability
Indonesia	Towards the protection of and promotion of the human rights of people with disability (PWD) through the empowerment of community based disabled people organisations (DPOs)
Indonesia	Protection and Promotion of the Rights of Indonesian Persons with disabilities
Jordan	Empowerment of DPO in Jordan
Lao	The Development of a Human Rights Based Culture for Disabled people in the Lao PDR - The way to greater inclusion and participation
Lao	Supporting the Lao Disabled Peoples Association to Build Capacity and Promote Greater Equity and Participation for Disabled People in Vientiane Province and Capital, Lao PDR

Liberia	Inclusive development and the realisation of basic human rights for persons living with disabilities in Liberia
Liberia	Promote the rights and inclusion of persons with disabilities in development issues in Liberia
Madagascar	Creation and Promotion of a Structured Associative Movement to Promote the Rights of Persons with disabilities, Madagascar
Maldives	Institutional Support (Phase 1), Maldives
Lebanon	Self advocacy for rights and access of persons with disabilities to social services in Middle East
Middle East (Jordan, Yemen, Egypt, Occupied Palestinian territories, Lebanon, Syria)	Strengthening self advocacy capacities for rights and equal opportunities of persons with disabilities in Middle East
Nepal	Empowerment and Social Change for Inclusion of Persons with disabilities in Nepal
Pakistan	Disability and Human Rights - Pakistan (Making it Work)
Sierra Leone	To promote the rights and inclusion of people with disability in development issues in Sierra Leone
Sierra Leone	Promotion of persons with disabilities inclusion in Sierra Leone
South Asia (Afghanistan, Bangladesh, India, Nepal, Pakistan and Sri Lanka)	UN Convention on the Rights of Persons with Disabilities HI South Asia Regional Coordination (SARC) Training Project
South-East Europe (Montenegro, Macedonia, Albania, Bosnia and Herzegovina and Serbia including the UN administered province of Kosovo)	Project Self Help and Advocacy for Rights and Equal Opportunities South East Europe - SHARE-SEE
West Africa (Burkina Faso, Niger, Mali, Senegal, Sierra Leone, Togo)	Rights, Citizenship, Solidarity and Inclusion of Persons with Disabilities in West Africa (DECISIPH).

Footnotes

-
- ↳ 1. Handicap International, 2011-2015 Strategy, chapter 2.4.4.
- ↳ 2. See also the section on “Why Supporting DPOs”
- ↳ 3. Under the coordination of Michael Guy, Handicap International UK.
- ↳ 4. See the list of projects reviewed in Annexes
- ↳ 5. Topics discussed included, inter alia: capacity development, knowledge management, awareness-raising, advocacy, research and studies, financial support, networking and coordination, and relations between HI and DPOs.
- ↳ 6. Regional projects in the Middle East : “Strengthening self-advocacy capacities for rights and equal opportunities of persons with disabilities in the Middle East” (Musawa Project) ; in West Africa : “Droits, Egalité, Citoyenneté, Solidarité et Inclusion des Personnes Handicapées” (DECISIPH) ; in Latin America : Construyendo Capacidades para Cosechar Derechos; in Maghreb: “Renforcement des capacités de plaidoyer pour la promotion des droits et l’égalisation des chances des personnes en situation de handicap en Algérie et au Maroc”.
- ↳ 7. Bill Albert, Briefing Note: the social model of disability, human rights and development, Disability Knowledge and Research, September 2004.
- ↳ 8. United Nations Convention on the Rights of Persons with Disabilities, Article 1. This is to be read in conjunction with the definition of disability in Preamble Paragraph (e): “Recognising that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (being part of the Preamble, this definition is however not binding for State Parties to the Convention).
- ↳ 9. Handicap International focus is to support SHG, DPOs and/or Federations in developing countries, which has led to develop partnerships with northern based or international level DPOs, such as the European Disability Forum (EDF) or the Arab Organisation of Disabled People (AODP).
- ↳ 10. The term «Independent Living» was taken from the 1959 Californian legislation which enabled people who had acquired a disability due to polio to leave hospital wards and move back into the community with the help of cash benefits for the purchase of personal assistance with the activities of daily living. For more information, cf. definition of independent living in the glossary.
- ↳ 11. A distinction is usually made between organisations of persons with disabilities and organisations working for persons with disabilities.
- ↳ 12. Stephen Lee Hodgkins [2009] ‘Unity, Equality, Capacity’ Disability Now
- ↳ 13. <http://www.disabilityrightsfund.org/node/35>
- ↳ 14. It is important to acknowledge that there is a potential conflict of interest if DPOs are both service providers and advocates. It is particularly the case when sources of funding for service provision are also a target for advocacy. In other words, if a DPO has received money from government to provide services, to what extent might this limit their independence

and ability to challenge these authorities? This is of particular importance for umbrella federations that are the primary interlocutor of the State. The point here is not that DPOs should not provide services but that the question of user and advocacy should not be forgotten or neglected. Situations may vary according to the history and structure of the disability movement, but the principle of separating functions has proven to be a facilitating factor. Whenever possible, advocacy and service delivery functions co-existing within the same organisation should be managed independently.

↳ 15. The UNCRPD is in fact the result of a double observation: 1) binding/ compulsory general international law did not explicitly address the issue of people with disabilities, even if implicitly covering all cases 2) specific international texts on disability were not sufficient as they were optional.

↳ 16. The UNCRPD is followed at the international level by two entities: the Conference of State Parties meets in New York under the aegis of the UN Department of Economic and Social Affairs (UNDESA); the Committee on the Rights of Persons with Disabilities meets in Geneva under the aegis of the OHCHR. This « double hat » is precious in the way that it links human rights with development with a clear will to see these rights concretely impact on the lives of persons with disabilities: "As a human rights instrument with an explicit social development dimension, the Convention on the Rights of Persons with Disabilities is both a human rights treaty and a development tool. The Convention identifies disability as an issue to be considered in all programming, rather than as a stand-alone thematic issue, and requires all States parties to implement measures ensuring full and equal participation of persons with disabilities in

society. However, disability-specific actions and programming may also be required, depending on national context." UN General Assembly, A/63/133, July 2008.

↳ 17. Catherine Dixon, Marianne Schultze, Access to services, a central theme to the UNCRPD, in Access to services for persons with disabilities in challenging environments, Supplement to the Seminar held in Amman (Jordan), December 2009, Handicap International.

↳ 18. See list of key stakeholders in the glossary

↳ 19. "A person who is discriminated against or marginalised is being deprived of opportunities from which others benefit. This is still too often the case for disabled people today. In developing countries, a vast majority of persons with disabilities are deprived of access to health services, rehabilitation, education, employment, housing, communication and transportation, which is a major development issue. Poverty won't be eradicated without mainstreaming disability issues in all development policies", Handicap International website.

↳ 20. It is planned that "during the period 2010-2015 the focus will be on increasing the involvement of beneficiaries and their representative organisations in development processes at various levels", Handicap International 2011-2015 Strategy; cf. also "Links with HI institutional framework documents"

↳ 21. See definition in glossary

↳ 22. See link with HI 2011-2015 Strategy

↳ 23. For more on the importance of this "twin-track" approach, see DFID, Disability, poverty and development, February 2000.

- ↳ 24. IDDC UN Task Group chaired by Handicap International, in "Inclusive Development and the Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities - reflection paper, contribution to the 5th Session of the Ad Hoc Committee", January 2005.
- ↳ 25. For more information on DPOs and access to services, see Handicap International, "Access to services for persons with disabilities in challenging environments", July 2010: http://drt.handicap-international.fr/uploads/tx_hidrtdocs/AccessToServicesAmman.pdf and "Access to social services for persons with disabilities in the Middle East, multi-stakeholder reflections for policy reform", 2009: www.makingitwork-crpd.org/fileadmin/user/content/DMI_Documents/DMI_Report_2009_final_version_17-5-2010.pdf
- ↳ 26. This accounts for the very close links between poverty and disability. This close relation is also recognised in the UNCRPD, cf. for example Preamble Paragraph (t).
- ↳ 27. cf. paragraph on Making it Work Part 2
- ↳ 28. HI Principles of Intervention (5.1)
- ↳ 29. HI Strategy 2011-2015 (4.)
- ↳ 30. HI Strategy 2011-2015 (2.2.)
- ↳ 31. HI Strategy 2011-2015 (2.4.4.)
- ↳ 32. HI Scope of Activities (3.)
- ↳ 33. HI Principles of Intervention (1.4.)
- ↳ 34. HI Strategy 2011-2015 (2.4.4.)
- ↳ 35. HI Principles of Intervention (1.5.)
- ↳ 36. HI Principles of Intervention (7.2)
- ↳ 37. HI Strategy 2011-2015 (2.2)
- ↳ 38. HI Strategy 2011-2015 (2.4.3)
- ↳ 39. Cf. Access to Services for Persons with Disabilities, Diana Chiriacescu, Maryvonne Debacker, Rozenn Botokro, Handicap International 2010. Cf. also Comprehensive and efficient P&O services, chapter on the service user.
- ↳ 40. Cf. Community-Based Rehabilitation Guidelines, WHO, ILO, UNESCO, IDDC, 2010. The Empowerment Component of these guidelines mentions specifically the following goal (p.51): "CBR programmes and disabled people organisations work together to ensure the implementation of the Convention on the Rights of Persons with Disabilities and community-based inclusive development".
- ↳ 41. Cf. Inclusive Local Development Policy Paper, Eric Plantier Royon, Priscille Geiser, Handicap International 2009 and A Guidance Paper for an Inclusive Local Development Policy, Charlotte Axelsson, Handicap International and IDDC 2008.
- ↳ 42. Sectoral mainstreaming, for example mainstreaming disability in disaster risk reduction, requires specific technical expertise to adjust sector practices and go beyond policy level. However, such initiatives also need to be conducted in close cooperation with DPOs, and should not be dealt with among international development actors only.
- ↳ 43. in support of the aims and objectives of the 1997 Anti-Personnel Mine Ban Treaty and the 2008 Convention on Cluster Munitions

- ↳ 44. Cf. inter alia: S. Ziegler, "Capacity Development and Partnership: overview and methodology", Handicap International, 2008: http://drt.handicap-international.fr/uploads/tx_hidrtdocs/RenfCapEng.pdf ; Handicap International work on Participatory Programming, Participatory Evaluation: N. Heeren, B. Crishna, "How are we doing? Participatory evaluation in the practice of Handicap International". (2001)
- ↳ 45. Fowler, Alan Partnerships: Negotiating Relationships, Occasional Papers Series No 32, Oxford: INTRAC, 2000
- ↳ 46. S. Ziegler, "Capacity Development and Partnership: overview and methodology", Handicap International, 2008: http://drt.handicap-international.fr/uploads/tx_hidrtdocs/RenfCapEng.pdf
- ↳ 47. S. Ziegler, "Capacity Development and Partnership: overview and methodology", Handicap International, 2008: http://drt.handicap-international.fr/uploads/tx_hidrtdocs/RenfCapEng.pdf
- ↳ 48. HI Technical Unit "Support to Civil Society" is currently working out a guideline on how to handle small grants/calls for proposals.
- ↳ 49. Constructive advocacy activities such as negotiation, alliance building, the use of media, networking, convincing, etc. should always be preferred to actions that confront opponents or even work with violent methods. HI does not engage in these types of methods, and we usually don't support such actions by DPO partners.
- ↳ 50. For more information, cf. see section 3 and Making It Work website: www.makingitwork-crpd.org
- ↳ 51. Where the Convention has not yet been ratified, this should be a priority for advocacy. This should not prevent using the UNCRPD as a reference to influence any legislation reform.
- ↳ 52. Julius Court, Enrique Mendizabal, David Osborne, Johan Young, Policy Engagement, How civil society can be more effective, ODI, 2006.
- ↳ 53. Disability Statistics Fight Invisibility, Disability Monitor Initiative Journal for South East Europe, Dec.2006 issue.
- ↳ 54. For examples of disability-related questions that can contribute to the global efforts of documenting persons with disabilities' situation, see the work of the Washington Group to produce internationally comparable general disability measure: <http://unstats.un.org/unsd/methods/citygroup/washington.htm>. In Europe, EUROSTAT has developed a standardised methodology producing comparable information across Member States of the EU.
- ↳ 55. Disability in the press: How disability and persons with disabilities are depicted in print media in Bosnia and Herzegovina, Montenegro and Serbia in 2006 - A discussion paper, Disability Monitor Initiative, Handicap International.
- ↳ 56. Cf. Practical guide for conducting a local participatory diagnosis- draft version, Handicap International.
- ↳ 57. See for example the National Disability Survey in Afghanistan 2005, Handicap International. The prevalence of persons with disabilities in the Afghan population varies from 2.2% when considering only people experiencing very severe difficulties in at least one of the dimensions (e.g. ability to take care

of oneself) used for the survey to 36.7% of the population when including people experiencing very severe, severe and moderate difficulties (and up to 58.9% when adding those experiencing mild difficulties).

↪ 58. For practical recommendations on UNCRPD monitoring and guidance for civil society monitors, see resources available on the website of the International Disability Alliance: www.internationaldisabilityalliance.org

↪ 59. As a development actor, HI tends to favour actions that contribute not only to the civil and political rights of persons with disabilities (such as the right to vote) but to the essential social, economic and cultural rights that impact their daily lives and are linked with key areas of our interventions.

↪ 60. Cf. page 13 and corresponding footnote.

↪ 61. Although peer counselling relies primarily on individual experience sharing, DPOs can engage more significantly in this activity seeking training or support from people trained in personalised social support. See also Barbuto R., Ferrarese V., Griffo G., Napoletano E., Spinuso G., Peer counselling (from victims of the history to protagonists of the life), Lamezia Terme (Italy), Comunità edizioni, 2006

↪ 62. Capacity Development, reference documents and resources, Handicap International, June 2010.

↪ 63. OECD-DC perspective on Capacity Development; <http://www.oecd.org/dataoecd/33/20/43950784.pdf>, June 2009

↪ 64. <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTPOVERTY/EXTMPOWERMENT/0,,contentMDK:20245753~pagePK:210058~piPK:210062~theSitePK:486411,00.html>

↪ 65. The World Bank, Empowerment and Poverty Reduction: a source book, 2002.

↪ 66. For more information, cf. Office of the United Nations High Commissioner for Human Rights, Frequently asked questions on a human-rights based approach to development: <http://www.handicap-international.fr/bibliographie-handicap/3ApprocheDroit/Approches/FAQen.pdf>

↪ 67. Disability Rights Promotion International: <http://www.yorku.ca/drpi/hRights.html>

↪ 68. A Basic Manual for Inclusive Development, Handicap International and the Inter-American Institute on Disabilities and Inclusive Development (IID), 2007.

↪ 69. IDDC UN Task Group chaired by Handicap International, in Inclusive Development and the Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities - reflection paper, contribution to the 5th Session of the Ad Hoc Committee, January 2005.

↪ 70. A guidance paper for an Inclusive Local Development Policy, IDDC (Handicap International, SHIA, Handikapp-Förbunden).

↪ 71. Open Society Institute Mental Health Initiative Glossary of Terms: <http://www.osmhi.org/?page=309>, as quoted in The right to live in the community: Making it happen for people with

intellectual disabilities in Bosnia and Herzegovina, Montenegro, Serbia and Kosovo, the Disability Monitor Initiative, Handicap International, 2008.

↪ 72. Rita Barbuto, Vincenza Ferrarese, Giampiero Griffò, Emilia Napolitano, Gianna Spinuso, Peer counselling, from victims of history to protagonists of life, Comunità Edizioni

↪ 73. "A situation of social participation corresponds to the full accomplishment of a routine lifestyle, resulting from the interaction between personal factors (deficiencies, incapacities and other personal characteristics) and environmental factors (facilitators and obstacles).", P. Fougeyrollas, Disability Creation Process.

↪ 74. World Health Organisation, International Classification of Functioning, Disability and Health (2001)

↪ 75. HI projects to support the disability movement, Synthesis of 29 projects developed by HI, Dorothy Boggs and Michael Guy, March 2009



End of the Appendices.

Photo credits

Cover: © Handicap International, Sierra Leone - Women with disabilities taking part in a meeting with the local authorities of Baiamaa, Kono District.

Page 8: © Priscille Geiser / Handicap International, Kathmandu, Nepal. (Demonstration on the 3rd of December, International Day of Persons with Disabilities).

Page 30: © J-J. Bernard / Handicap International, Senegal, Cabrousse, 10/2010. Inclusive Education Project. (Marie-Gilberte Badji, a girl with multiple disabilities, 14 years old, included in an ordinary school.)

Page 45: © S. Ziegler/ Handicap International, « Monde Radieux », Sokodé, Togo. (Member association of the national federation FETAPH).

Page 68: © S. Baux / Handicap International Decisiph project (50th anniversary of Mali, for health services accessible to persons with disabilities).

Editor

Handicap International
14, Avenue Berthelot
69361 LYON Cedex 07

Printing

Graphiconseil
2, Petite rue de la Rize
69100 Villeurbanne
France

Imprint in October 2011

Registration of copyright October 2011





Support to Organisations Representative of Persons with Disabilities

This policy paper describes Handicap International's mandate and values in operational terms as applied to supporting organisations representative of persons with disabilities. It presents the approaches and references for Handicap International's actions, choices and commitments. It aims to ensure coherence in terms of practices whilst taking into account different contexts. Essentially this is a guidance document for programme staff which defines the topic and outlines the target populations, methods of intervention (expected results, activities) and indicators for monitoring and evaluation. This policy aims to ensure that all projects carried out by Handicap International programmes are consistent with the methods of intervention presented.

HANDICAP INTERNATIONAL
14, avenue Berthelot
69361 LYON Cedex 07

T. +33 (0) 4 78 69 79 79
F. +33 (0) 4 78 69 79 94
contact@handicap-international.org