

CHILDREN WITH A DISABILITY¹



Picture by Gilbert Vogt Bénin 1996 - Orphan deaf dumb blind

INTRODUCTION

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GENERAL INFORMATION

It is with no doubt that persons, and particularly children, with disabilities, have historically experienced severe forms of abuse and discrimination, violation of their human rights, social exclusion and maltreatment. Children with disabilities are one of the most acknowledged categories of children who are found in difficult social situations all around the world.

A Convention specifically designed to protect people with disabilities has only recently been drawn up and set into force, in 13 December 2006. This is the UN Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol, and specific reference to children is provided in its Article 7.² The Convention as a whole is premised on the fundamental human rights values of dignity, equality, social justice and self-determination, and constitutes the first holistic human rights approach

¹ Project Work of the Master of Advanced Studies in Children's Rights (2007-2008), Institut Universitaire Kurt Bösch, Université de Fribourg.

² Article 7, CRPD states: "1. States Parties shall take all appropriate measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. 2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration. 3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right".

to disability. Other human rights instruments include provisions for the protection of persons with disabilities, not least the CRC, with its context-specific article No. 23, which requires states to support disabled children in enjoying a full and decent life, and obliges them to ensure the establishment of appropriate resources to ensure the full and unobstructed individual development of these children.³

It is with no doubt that both conventions strive to ensure that persons (children) with disabilities enjoy equal rights and equal opportunities in life, as other persons do. Disability, in this sense, is a crosscutting issue, and should be viewed, in the case of children, through the fundamental rights of nondiscrimination and participation, and the principle of the best interests of the child. In parallel, human rights respect for disabled children must be addressed in all other facets of human life, as disability often becomes a factor supporting exclusion and violence, as well as entails health-related dangers against the well being, and even the life of children.

The CRPD refers to 'persons with disabilities' as *including* 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." The non-provision of a solid definition on disability was purposeful, as the issue of disability becomes all the more crucial and multi-faceted in the modern world. Some societies have already stretched the definition of disability to include many forms of health-related impairments, such as, for example, HIV-AIDS and diabetes, while others maintain a much narrower understanding. Principally, there should be no definition, and this was perhaps the understanding of the drafters of the Convention, because the purpose of it was to ensure access to established human rights principles, and this should not be grounded again on any form of 'separation' or 'discrimination'.

Children with disabilities are found in all societies of the world. It is a common feature that, whether intentionally (i.e. linked to cultural or religious or social dispositions) or unintentionally, many children with disabilities remain invisible and excluded. In some societies their birth may even never be registered.

Apart from individual factors, it is a sad reality that societies have been largely unwilling and scientifically underdeveloped to deal with the various facets of disability in a holistic, human-rights integrated way. Until recently, disability was treated predominantly under a medical perspective that overlooked the many important social benefits that could be achieved from the successful integration of persons with disabilities in the society.

As scientific (medical, but most crucially, sociological, educational, and legal) progress is achieved, and as states are gradually committing themselves into respecting the rights of disabled persons and into establishing appropriate structures for them, it is hoped that children with disabilities will come out of obscurity and will be given the opportunities they deserve to prosper and develop.

FREQUENTLY ASKED QUESTIONS

Who are persons with disabilities?

According to the recently adopted UN Convention on the Rights of Persons with Disabilities (2006), persons with disabilities include those who have long-term physical, mental, intellectual or sensory

³ Article 23, CRC states: "1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. 2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child. 3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents and others caring for the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development. 4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capacities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries."

impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. WHO has defined, more narrowly and from a medical point of view, individuals with disability as those who have a physical, sensory (deafness, blindness), intellectual or mental health impairment.

What are the main international human rights instruments and bodies for the protection of Children with Disabilities?

The UN Convention on the Rights of Persons with Disabilities (2006) and the UN Convention on the Rights of the Child (1989) – which was the first human rights treaty to specifically refer to disability. The UN Committee on the Rights of the Child requires states to periodically report on their activities, including as concerns the protection of children with disabilities. The Committee has also held a General Discussion Day, in 1997, on children with disabilities. The findings of this discussion resulted in the adoption of a General Comment by the Committee, specifically addressing the challenges of disability in children (General Comment No. 6).

How many are the children with disabilities around the world?

The number of children and adolescents with disability is significant. Current estimations give a ratio of 1/10. Some 200 million children, meaning 10% of the world's youth, are born with a disability or become disabled before the age of 18.

Where are they?

Children with disability are in all societies of the world. More than 80% live in developing countries and have no access to appropriate services.

What are the causes of disability?

The causes of disability are multiple. Disability can occur at birth, from genetic disorders, but many forms of disability are preventable, and may occur because of lack of preventive health care services (i.e. polio, malnutrition, micronutrient deficiencies) or on account of social situations (armed conflict, war, landmines, poverty). It must not be overlooked that violence is often a cause of childhood disability.

What kind of discrimination can they face?

Apart from dire social exclusion, many children with disabilities have no access to services, to education, to cultural and recreational activities, to vocational training and to other forms of important social and developmental activities. Many of them are in institutions, while in many societies the mere birth of a child with disability is linked to cultural, religious and social beliefs (i.e. 'curse', 'bad blood', etc) that lead to an ostracism of these children from their community environment.

How is social exclusion for disabled persons perpetuated?

Primarily, children with disabilities do not have access to schooling and education. It is estimated that less than 2% of children with disabilities today receive an education, while the remaining 98% are out of school. 1% of these children are completely illiterate. Societies have failed to respond to disability in a 'human rights-integrated' manner, taking into account the abilities and potentials of such young people, and have addressed disability very much in a medical sense. Another aspect that has supported exclusion is the marginalisation of children (and persons) with disability in state policies and programmes (with the introduction, for example, of 'special schools', 'special institutions', etc) and the limited respect to the principle of non-discrimination.

What forms of violence can children with disability face?

Despite the fact that research in this field remains very limited, it is widely acknowledged that children with disabilities are at increased risk of becoming victims of violence, not least because they are less able to defend themselves. Current research suggests that violence against children with disabilities occurs at annual rates at least 1.7 times greater for these children than for their non-disabled peers.

Violence can occur in various settings (family, community, institutions, work place), and in many forms (physical, mental, emotional).

What are the core rights of children that must be fully respected for children with disabilities?

All articles of the CRC are critically important and apply to children with disabilities. In order, however, to demolish the spells of the past in discriminating children with disabilities, states and societies must first and foremost respect the principle of non-discrimination, uphold the idea that the best interests of the child must prevail in all actions affecting him/her, and must give generous opportunity and possibility for children with disabilities to voice their opinion and to have their views heard and respected. The marginalisation of children with disabilities will not be solved unless it is recognized that these children must be included in the overall decision making process.

What are some of the suggested 'solutions'?

Societies must recognize the importance of this issue, and must build up their research, documentation and data systems to assess the width of the situation, and its various aspects. Children with disabilities and their families must be empowered to participate in policies and programmes. States must commit resources to enhance services, and must develop better policies for training and capacity building. The overall approach must also have a preventive side and should not only tackle the consequences of disability. It is critically important to put forward positive images of children with disabilities, and to raise public awareness.

DOCUMENTATION

The following text provides a selection of sources related to children with disabilities in various geographical settings.

LAWS AND NON-BINDING POLICY-MAKING TEXTS

NATIONAL

• SWITZERLAND:

- Protection of mineurs Act 2004 (Canton of Vaud): This law places precautionary measures on factors that may endanger the wellbeing of minors; it aims to ensure, in association with the parents, the protection and the assistance of the minors in danger in their development, by facilitating the autonomy and the responsibility of families; it strives to insure the protection of the minors living outside the family circle.
- Law on Special Education 1977 (Canton of Vaud): Special education is intended for children and teenagers from whom the state requires a particular training, notably because of a disease or of a mental, psychic, physical, sensory or instrumental handicap. Special education tends to facilitate the autonomy, the acquisition of knowledge, the development of the personality and the opening to others, of such children.
- FRANCE:
 - Law n°2005-102 of the 11th February 2005. This law guaranties a true equality of chance to access school and transports, culture and leisure, most importantly it shows the recognition of the full citizenship of people with a handicap. About schooling, it is not a simple recognition of rights any more. Every child must be registered in the nearest school from his/her home. The system should allow every child to have a reception and accompaniment adapted to his/her needs, in particular to the nature of his/her handicap: motor, mental, hearing, visual, cognitive, multiple handicaps... The school education appears in this law as having a decisive impact on the person with a handicap in the society.

• NEPAL:

- The Disabled persons (welfare and protection) Act 1982 (DPWA): Comprehensive legislation which grants some rights and facilities to the PWDs including education rights, health facilities, employment opportunities, self-employment facilities, tax-exemption facilities, travelling facilities and free legal aid services. Author: Government of Nepal/Enacted by the legislature.
- The Disabled persons (welfare and protection) Rules, 1994: Delegated legislation to implement the objectives of The Disabled Persons (welfare and protection) Act. **Author:** Ministry of Women, Children and Social Welfare / endorsed by the council of the Ministers, Government of Nepal.
- National Plan of Action for Children (NPA)-2004/05-2014/15: The NPA has been prepared having the vision that children enjoy their rights and realise their full potentials in societies which are fit for children. Author: Central Child Welfare Board, Ministry of Women, Children and Social Welfare / endorsed by the council of the Ministers, Government of Nepal.
- Information of Government of Nepal on disability issues: Nepal government recent policy on disabilities.

• ALGERIA:

- Loi relative à la protection et à la promotion des personnes handicapées adopted by the Parliament in 2002 and signed by the president Abdelaziz Bouteflika, the law protecting handicapped persons still does not have an application text. The law allows a financial help of 300 DA to people with a handicap or their families without any other income. This help is not sufficient to provide for the person with a handicap's needs, in particular children.

• QUÉBEC:

 Loi assurant l'exercice des droits des personnes handicapées en vue de leur intégration scolaire, professionnelle et sociale The law gives a definition of a person in a handicapped situation, it considers those persons as "all person having a deficiency leading to a significant and persistent incapacity subject to encounter obstacles in accomplishing common activities". The law doesn't include any specific articles to children in a handicapped situation.

Example of good practices:

• SCHOOLS OF MARTIGNY, SWITZERLAND:

In the Martigny school project the teachers adopted a charter, that stipulates at its paragraph 5 that: "the school refuses all forms of exclusion and organises itself in a way to allow all children to follow a class with friends of his/her one age". The Headmaster adds that "this is a choice based on ethical and social principles before being a pedagogical choice; it is part of the educative mission of the school that wants to refuse exclusion and that wants to promote solidarity, mutual aid and tolerance".

In practical that means that in Martigny there is no more "specialised" classes (adaptation, help, development, observation... or other, depending on the local terminologies). On the other hand, the structures put into places must enable the maintaining of all the children in ordinary classes as long as it is the wish of the concerned parent and that efficient accompaniment measures are offered.

The class is left in the care of the two teachers one of whom is especially trained in curative pedagogy. The children and their two teachers share all day the same classroom and the same activities.

• LUXEMBOURG:

- In Luxembourg the services working in the field of the precocious help propose specific programs for the siblings of children in a handicapped situation: day of meeting and exchange, information and awareness – raising programs, individualised intervention, and lectures.
- Moreover, in the dependence-assurance, psychological advices to the family circles of children in handicapped situation are planned to support close relatives, and therefore also the siblings.

• ITALY:

- When a child in a handicapped situation is confronted to exclusion, it is often all the family who is socially excluded: social life can be less developed because the family fears the look of the others, giving up on leisure and holidays because of the inaccessibility of the structures, transports, cultural events, etc.
- This is why Italy has created awareness-raising programs from a young age and compulsory at school, school inclusion, and accessibility to structures, sport and leisure activities, and a general promotion of an inclusive and accessible society, which is essential for the integration of children with a handicap but also the integration of their family.
- It is also to develop the well-being of the brothers and sisters of a child in a handicapped situation, that all the siblings of a child in a handicapped situation have priority access to nurseries, full-time schools, holiday centres, etc.

INTERNATIONAL

Convention on the Rights of persons with Disabilities and its Optional Protocol (United Nations).

JURISPRUDENCE

• Australia:

Children in sports: Links to many jurisprudences on sex-discrimination and children with disabilities in sports situations; pregnant girls and sports. (Coming up)

UN REPORTS AND UN TREATY BODIES TEXTS

• Children with disabilities, Day of General Discussion, CRC/C/GC/9, 27 February 2007.

The Committee of the Rights of the child, considering that among 2 billion children in the world 100 million have disabilities, decided to devote a day of general discussions to the rights of the children with disabilities as it represents a powerful opportunity to challenge the invisibility of those children. It aimed to provide a high-profile focus on the rights of children with disabilities to social inclusion; their right not be discriminated against on the grounds of their handicap. The discussion focused mainly on article 23 of the Convention. Recommendations also available in A/AC.265/2006/4. Annex II.

• Violence against Disabled Children, UNICEF and the United Nations, New York, July 28, 2005.

The report presents the findings of the thematic Group on Violence against Disabled children, convened by UNICEF at UN Headquarters in New York and charged with the task of providing comments and recommendations on violence against Children.

 Specific groups and individuals: Other vulnerable groups and individuals, Report of the United Nations High Commissioner for Human Rights on progress in the implementation of the recommendations contained in the study on the human rights of persons with disabilities, E/CN.4/2003/88, 14 January 2003.

In its resolution 2002/61, the Commission on Human Rights requested the Office of the High Commissioner for Human Rights (OHCHR) to report to the Commission at its fifty-ninth session on progress in the implementation of the recommendations contained in the study on the human rights of persons with disabilities. The report shows that the implementation of these recommendations may have a considerable impact on the promotion and protection of the human rights of persons with disabilities.

 Progress in the implementation of the recommendations contained in the study on the human rights of persons with disabilities, Report of the Office of the High Commissioner for Human Rights, E/CN.4/2004/74, 15 December 2003.

In its resolution 2003/49, the Commission on Human Rights requested the Office of the High Commissioner for Human Rights (OHCHR) to report to the Commission at its sixtieth session on progress in the implementation of the recommendations contained in the study on the human rights of persons with disabilities and of the programme of work of the Office in relations to the human rights of persons with disabilities. The report provides examples of the progress made by the different stakeholders in implementing the recommendations but an assessment of the actual impact of the study will only become possible in the years to come.

 Study on human rights and disability – The current use and future potential of United Nations human rights instruments in the context of disability, 2002, Gerard Quinn and Theresia Degener with Anna Bruce, Christine Burke Dr. Joshua Castellino, Padraic Kenna, Dr. Ursula Kilkelly, Shivaun Quinlivan.

Chapter 8 deals with the Convention on the Rights of the Child insofar as it is relevant to the children with disabilities. The Convention is unique among the human rights treaties in that it contains a specific article on disabled children 9art.23).

 Children with disabilities/CRC and disability/non-discrimination/integration, UN Doc CRC/C/GC/9 27 February 2007.

The general comment is meant to provide guidance and assistance to State parties in their efforts to implement the rights of children with disabilities in a comprehensive manner which covers all the provisions of the Convention.

• The Protection of Older Persons and Persons with Disabilities, UNHCR document number: EC/58/SC/CRP.14, issued on 06 June 2007.

The paper examines the challenges faced by older persons and persons with disabilities in accessing international protection and assistance, in cases of displacement. It reviews current policies on the protection of displaced older persons and those with disabilities; highlights the main protection challenges faced by these individuals; and outlines efforts made by UNHCR and partners to respond to these challenges.

 <u>NGOs and UN Agencies – Assisting Persons with Disabilities</u>, United Nations High Commissioner for Refugees (UNHCR)

The publication is a non-exhaustive reference list of organizations working with for persons with disabilities worldwide.

NGO'S PUBLICATIONS

Hospital and Rehabilitation Centre for Disabled Children (HRDC) Nepal, Yearly activities, Annual Report. Annual activities of HRDC Nepal. This is only the specialised hospital in Nepal, which significantly helps disabled children in very professional manners. The services and facilities it provides are appreciable.

FACT SHEETS, SURVEYS AND GUIDELINES

- Karua Foundation, Nepal, Survey's report 2007-2013 <u>Saving children from disabilities, one by</u> <u>one</u>..
- Government of Nepal /UNICEF Nepal, 2001, <u>A Situation Analysis of Disability in Nepal</u>. This is the first official study report of the government of Nepal on disabilities.
- UNICEF, Survey's report 2013, <u>The State of the Word's children, Children with disabilities</u>

NETWORKS, INTERNET WEBSITES AND OTHER SOURCES

<u>Handicap International</u>, is an association that works tirelessly alongside disabled and vulnerable people to help meet their basic needs, improve their living conditions and promote respect for their dignity and fundamental rights.

Inclusion International, The international organisation of people with intellectual disabilities and their families.

EACD - European Academy of Childhood disability, is an academic association of professionals working with.

CONCLUSIONS

The above citation of available study and documentation around the topic of children with disabilities is only a minimum sample of what is, and what will be available, globally, for potential researchers. Both these thematic areas are increasingly gaining visibility and interest, thus many more documents and references are to be found in libraries and in the internet, as well as in binding and non-binding legal texts.

Some conclusions can be drawn from this study on research and bibliography conducted here. First, it can be seen that, as the Convention on the Rights of the Child and other human rights instruments gain additional years of existence and are established in individual and collective consciousness, research on children-related topics takes a significant 'human rights' shift. Thus, both the positive sides, but primarily the negative sides of situations in which children are involved are viewed through the 'human rights approach' discipline. This is extremely important, as, for example, it helps analysers codify the problem, support a child-protection position through the existence of legal norms, and propose solutions and measures on the basis of universally agreed standards. It can now be established, for example, that coercing a child into performing better within the sports area is not only ethically wrong, but is in violation of specific articles and rights found in the Child Rights Convention. This approach is giving a tremendous potential and gear in the research and development sphere.

Secondly, we are able to see that with the increasing mobility of the society at large, empirical documentation is developing rapidly, in parallel with theoretical approaches. In specific, the work of the numerous non-governmental organizations which are active in different disciplines concerning children's activities, children's rights and children's situations, is producing, through project development, a vast bibliography of empirical observation and practice, which complements the role of the theory. As such, there are increasingly many NGO networks and websites that can support researchers find practical applications through projects and good practices all around the world.

Lastly, it is very important to note that there are some critical issues on children's rights and status, which 'cut across' theory and research on all levels. These are, primarily, the issues of 'participation', 'gender' and 'social integration', and they are critical first of all because they represent three of the most fundamental principles and rights enshrined in the Convention (participation, non-discrimination, development and best interests), and secondly because they (their absence) can be either a cause for child rights violation or the desired, human rights related, outcome. Most children's issues, including of course children in sports, are affected by the minimum opportunities children have in participating

actively in their environment, inasmuch as they are affected by gender discrimination. In parallel, in many cases, children are excluded from integrating fully and actively in their societies, for reasons of discrimination, exploitation or lack of accessibility to goods and services. All of these connections are increasingly addressed in modern research, and are likely to be further expanded to demonstrate and prove that respect for human rights is also dependent on social policy, development and social openness.

As this project work has had as its objective to establish a basis for an evolving website on this topic, it is hoped that the inclusion of new information, as it becomes available, will give endless opportunities to future researchers in evaluating what is actually available.

Fribourg, 28 May 2008, MCR Student Team:

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(Rectified ACM / 16.12.2016)