



# See Me, Hear Me

A guide to using the UN Convention on  
the Rights of Persons with Disabilities  
to promote the rights of children



**Save the Children**

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the Rights of Persons with Disabilities  
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**The International Save the Children Alliance is the world's leading independent children's rights organisation, with members in 28 countries and operational in more than 100. We fight for children's rights and deliver lasting improvements to children's lives worldwide.**

### **Save the Children's work with children with disabilities**

A commitment to fight for the rights of disabled children has been central to the mission of Save the Children since its inception in 1919. Work with and for disabled children has included addressing rights to inclusive education, play and leisure, rehabilitation, family support, alternatives to corporal punishment and other degrading and humiliating treatment and parent/teacher support. Media campaigns and advocacy to stakeholders and duty-bearers are also conducted in order to realise the rights of disabled children and improve support to their families. More recently, Save the Children has developed innovative approaches to the participation of children with disabilities to influence decision makers.

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Cover photo: Christian, 6, from Colombia, was turned away from school because of his physical disability. He now attends a nursery school that is supported by Save the Children. (Photo: Dan Alder/Save the Children)

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# Foreword

The Convention on the Rights of Persons with Disabilities represented the culmination of many years of consistent advocacy by the disability community in their struggle for recognition of their rights. Both the strength of the text, and its signature on the opening day in March 2007 by representatives of 81 countries, are testimony to the effectiveness of their advocacy in highlighting the urgent need for action to address the human rights violations they face in countries throughout the world. The Convention marks a turning point: it asserts that the rights of people with disabilities must be recognised and respected on an equal basis with others; it provides a comprehensive and coherent analysis of the measures needed to overcome the discrimination, poverty, violence, neglect, isolation and denial of independence and human dignity they face. It also provides mechanisms to hold governments to account in implementing those measures.

Importantly, the Convention provides a clear focus on the obligations of governments in ensuring that the rights of children with disabilities are protected. The Committee on the Rights of the Child, in its reviews of State Party reports, has found consistent evidence of the challenges faced by children with disabilities in realising their rights. There are an estimated 200 million children with disabilities across the world, more than 80% of whom live in the developing world with little or no access to healthcare or education. They are disproportionately likely to live in poverty, experience physical and sexual violence, be

denied a voice, and lack access to family life, information, play, sport, art or culture. Indeed, in the overwhelming number of countries reviewed, it has been necessary to make recommendations for action to overcome neglect or violation of rights.

The Committee on the Rights of the Child therefore strongly welcomes the adoption by the United Nations General Assembly of the Convention on the Rights of Persons with Disabilities, which emphasises that the barriers to the enjoyment of rights lie not in the disability itself, but in the social, physical, economic, cultural and attitudinal barriers faced by people, including children, with disabilities. It will serve as a powerful and complementary tool to the Convention on the Rights of the Child: while the latter establishes the human rights of children, the Convention on the Rights of Persons with Disabilities provides the detailed elaboration of the measures needed for their realisation. The Committee hopes that there will be rapid and widespread ratification of the new Convention and its optional protocol.

However, adoption and ratification, although vital, is obviously not sufficient. The Convention must also be implemented. Civil society organisations will continue to play a central role in ensuring that this happens. The advocacy that has been so successful at international level now needs to be replicated at national level, with those working for disability and for children's rights collaborating and utilising each others' knowledge and expertise. Joint advocacy

will have the greatest impact in persuading governments to introduce the necessary legislation, policies, resources, public awareness campaigns and government structures to achieve real change in the lives of children with disabilities.

This guide represents a significant contribution towards that process. Its detailed analysis of the two Conventions, and their interrelationship, together with practical guidance on strategies for advocacy and illustrations of good practice,

make it an invaluable tool for practitioners committed to bringing an end to discrimination against children with disabilities. The hurdles to be overcome are very high. This guide should contribute to ensuring that they are not insurmountable.

**Yanghee Lee**

Chair of the Committee on the Rights of the Child and Professor of Child Psychology and Education, Sungkyunkwan University, South Korea

# About the author

Gerison Lansdown is an international children's rights consultant and has published and lectured widely on the subject of children's rights, both nationally and internationally. On behalf of Save the Children, she was actively involved in the drafting of the Convention on the Rights of Persons with Disabilities from the perspective

of children with disabilities. She is currently vice-chair of UNICEF-UK, an associate of the International Institute for Child Rights and Development in Victoria, and co-director of CRED-PRO, an international initiative to develop child rights educational programmes for professionals working with children.

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# Introduction

There are an estimated 200 million children with disabilities in the world, out of a global population of about 2 billion children.<sup>1</sup> In other words, approximately 10% of the total population of children, the majority of whom live in developing countries, are born with a disability or become disabled during childhood. A significant number of the impairments, and consequent disability, experienced by children are directly caused by preventable factors, including poverty, malnutrition, violence, accidents, trauma, war and preventable disease.

So, what are the implications for these children? Children with disabilities are not valued the

same as other children, and are widely seen as not being capable of, or needing, love, affection, humour, friendship, cultural and artistic expression and intellectual stimulus. They are segregated, marginalised and isolated, and can be subjected to physical and sexual violence with relative impunity. Rates of early death for children with disabilities may be as high as 80% in countries where mortality rates for under-fives as a whole have decreased below 20%. Children with disabilities are defined by and judged by what they lack rather than what they have. Their consequent isolation can be extreme. Their very existence is widely denied – too often, their births are not registered,

## **A snapshot of the lives of children with disabilities**

- Up to 200 million children globally have a disability.<sup>2</sup>
- Children with disabilities are disproportionately likely to live in poverty.<sup>3</sup>
- Children with disabilities are disproportionately vulnerable to both physical and sexual abuse.<sup>4</sup>
- Mortality for children with disabilities may be as high as 80% in countries where under-five mortality as a whole has decreased to below 20%.<sup>5</sup>
- Parents and medical professionals who murder children with disabilities often receive reduced sentences and use ‘mercy killing’ defences – this reflects the belief that the lives of children with disabilities are not of equal value to other children.<sup>6</sup>
- At least 90% of children with disabilities across the developing world have no access to education.<sup>7</sup>
- Access to justice is routinely denied because children with disabilities are not considered credible witnesses.<sup>8</sup>

they are not recorded in census data, they are hidden away in back rooms or abandoned in institutions. These processes serve to dehumanise them. The cumulative impact is to deny children with disabilities respect for their dignity, their individuality, even their right to life itself. But it also dehumanises society. No society can lay claim to civilisation, humanity and justice when it continues to subject a significant minority of its people to such abuse and neglect.

The causes of the rejection lie deep in the social, economic, cultural and psychological roots of all cultures – such as a dislike of or hostility to difference, a belief that disabilities derive from curses or punishments, guilt, fear of ‘contamination’, reluctance to accept the responsibility for caring, poverty and lack of support. Discrimination against children with disabilities has existed in every community throughout history. But it is not inevitable. And the 21st century has provided an unprecedented opportunity to bring about change.

On 13 December 2006, after four years of negotiations, the United Nations (UN) General Assembly adopted a new Convention to protect the rights of people with disabilities round the world. This Convention is the first major human rights treaty of the 21st century, and addresses civil, political, social, economic and cultural rights. It opened for signature on 30 March 2007, and entered into force on 3 May 2008 after having been ratified by 20 countries. Former UN Secretary-General Kofi Annan has hailed the adoption of the Convention “*as a historic achievement for the 650 million people with disabilities around the world*”.

However, the new Convention will only be effective for children with disabilities if they themselves, their caregivers, local communities,

civil society organisations, and children’s and disability rights advocates know that it exists and how to use it. Save the Children has responded to the need for information by developing this guide to help children with disabilities and their advocates use the new Convention to claim their rights and begin to build inclusive societies that are equally respectful of all children (see Appendix 3 for details of the process for the development of this guide).

### **Please note**

In the Convention on the Rights of Persons with Disabilities (CRPD), children with disabilities are described as including those who have long-term impairments which, in interaction with physical, social, economic or cultural barriers, may limit their ability to participate fully in society on an equal basis with others. The following are therefore included:

- children with physical impairments, for example, wheelchair users
- children with psychosocial conditions such as depression
- children with intellectual impairments or learning disabilities
- children with sensory impairments, including those who are deaf, deafblind and blind.

Some children have multiple disabilities. They are often the most neglected and vulnerable children. It is important to recognise that they have the same rights as all other children and efforts must be made to ensure that the necessary action is taken to enable them to realise their rights and fulfil their potential.

## Outline of this guide

This guide is intended for use by child and disability rights advocates, and civil society organisations. It will also be of use to government in interpreting and implementing the rights of children with disabilities. It does assume some knowledge or understanding of advocacy and is not written for children themselves. This guide covers the following topics:

**A glossary** – explaining some of the commonly used words in human rights law and practice

### Part one: The development of rights for children with disabilities

**1** – A brief introduction to human rights – where do they come from and what do they mean?

**2** – Historical overview of the rights of people, including children, with disabilities – a brief review of the developments at international level that have led to an understanding of disability as a human rights issue, and the contribution of the UN Convention on the Rights of the Child (UNCRC) to increased recognition of the rights of children with disabilities

**3** – Development of the UN Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol – an overview of the history of the Convention, how it came about,

the role played by the disability community and children with disabilities, and the inclusion of issues concerning children with disabilities

**4** – Key provisions – a brief description of all the articles in the Convention and its Optional Protocol, and their meaning

### Part two: Implementing the rights of children with disabilities

**5** – Responsibility for implementation of the rights of the CRPD – a detailed analysis of the key responsibilities of governments and the action they are expected to take after ratifying the CRPD and the UNCRC, as well as the responsibilities of other actors in the lives of children with disabilities

**6** – Advocacy to promote implementation – suggested strategies for action to ensure effective advocacy to promote the realisation of the rights of children with disabilities

**7** – Understanding the rights of children with disabilities – an analysis of how to use the CRPD and the UNCRC together in order to understand the key rights of children with disabilities and advocate effectively for their realisation

Appendix 1 gives the full text of the Convention on the Rights of Persons with Disabilities. Appendix 2 lists useful sources of information for professionals working in this area. Appendix 3 sets out how this guide was developed.

# Glossary

**Accession** – the way in which a country can become a ‘State Party’ (see below) to an international convention. Normally a country will sign and then at a later date ratify the convention to which it wants to become a State Party. Accession refers to a country signing and ratifying both at the same time.

**Adoption** – when the text of a convention is officially finalised and formally accepted by the United Nations General Assembly.

**Child participation** – an ongoing process of children’s expression about, and active involvement in, decision-making at different levels in matters that concern them. It requires information-sharing and dialogue between children and adults based on mutual respect. It requires that full consideration of their views is given, taking into account the child’s age and maturity.

**Civil society** – refers to a broad range of non-governmental organisations and institutions, community-based organisations, grass-roots movements, including disabled people’s organisations, etc.

**Committee on the Rights of Persons with Disabilities** – the international body established by the Convention on the Rights of Persons with Disabilities (CRPD) with responsibility for monitoring implementation of the Convention at national level. It will consider reports from States Parties on the measures they have taken to implement the

Convention and in some instances will be able to consider individual or group complaints of violations of the Convention.

**Communication** – in the CRPD this includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

**Concluding observations** – the document produced by a treaty body (in this case, the Committee on the Rights of Persons with Disabilities, as mentioned above), following its dialogue with a State Party on its progress in implementing a treaty. It will contain comments on positive developments as well as issues of concern, and will make recommendations for future action by the State Party.

**Convention** – a legally binding document, in writing, between two or more countries. Also sometimes known as a ‘treaty’, ‘protocol’, ‘covenant’, ‘agreement’ or ‘pact’. When a United Nations human rights convention is adopted (see above), international norms and standards of human rights are created. At this point, countries can then sign and ratify or accede to the convention, taking on a set of legal obligations to implement it. The United Nations or other relevant body can censure governments that violate the standards in a convention.

**Discrimination on the basis of disability** – any distinction, exclusion or restriction on the basis of disability that 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 (see *below*). Discrimination can be both direct and indirect.

**Duty bearer** – when something is defined as a right, it means that someone (‘claim-holder’) has a claim to have that right realised. The person or body who has the responsibility for ensuring the fulfilment of the right is known as a duty bearer. Duty bearers are primarily State actors and institutions at various levels of the governance structure, but also include non-state actors who are in a position to influence the rights of others. For instance, parents, teachers, the Ministry of Education and Parliament are all duty bearers with obligations to ensure that children with disabilities are able to realise their right to education.

**Economic and Social Council (ECOSOC)** – this was established under the United Nations Charter as the principal organ to coordinate economic, social, and related work of the 14 United Nations specialised agencies, functional commissions and five regional commissions. The Council also receives reports from 11 United Nations funds and programmes. The Economic and Social Council serves as the central forum for discussing international economic and social issues, and for formulating policy recommendations addressed to Member States and the United Nations system.

**Entry into force** – when a convention has received the necessary number of ratifications by individual countries, it will enter into force for those countries (ie, it becomes legally binding upon those countries that have ratified it). The CRPD came into force on 3 May 2008, one month after the required 20 countries had ratified.

**General Assembly** – this is the main decision-making body of the United Nations. Each United Nations Member State is entitled to be represented in the work of the General Assembly, and each United Nations Member State has one vote in decisions taken by the General Assembly.

**Habilitation and rehabilitation** – habilitation involves learning skills that will enable a person to function in society. These kinds of programmes usually target children born with disabilities. Rehabilitation means restoring capacity and ability. This generally applies to someone who has to readapt to society after acquiring a disability. Habilitation and rehabilitation are usually time-limited processes that are tailored to the individual.

**Human rights** – these are the rights that everyone has by being a human being. You do not have to be a member of a particular group, and nobody needs to give you your rights. Everyone is automatically entitled to enjoy the full range of human rights.

**Human Rights Council** – an inter-governmental body within the United Nations System that was established in 2006. It has replaced the United Nations Commission on Human Rights, and is a subsidiary body of the United Nations General Assembly. Based in Geneva, its main purpose is to make recommendations to the General Assembly about situations in which human rights are violated.

**International cooperation** – the term used to refer to the various ways in which governments can work together to fulfil their obligations or goals. International cooperation can take the form of international development aid, but it also relates to the sharing of experiences, technologies, and knowledge – all of which can be done between and among both developed and developing countries.

**Language** – in the CRPD this includes spoken and signed languages and other forms of non-spoken language.

**Office of the High Commissioner for Human Rights (OHCHR)** – a department of the United Nations Secretariat that is mandated to promote and protect the enjoyment and full realisation, by all people, of all rights established in the Charter of the United Nations and in international human rights laws and treaties. The mandate includes preventing human rights violations, securing respect for all human rights, promoting international cooperation to protect human rights, coordinating related activities throughout the United Nations, and strengthening and streamlining the United Nations system in the field of human rights. In addition to its mandated responsibilities, the Office leads efforts to integrate a human rights approach within all work carried out by United Nations agencies.

**Optional protocol** – this is a separate, but linked agreement that addresses additional issues not covered by the main text of a convention, or which elaborates provisions in the main convention. For example, the CRPD has an Optional Protocol that gives the Committee on the Rights of Persons with Disabilities the power to hear individual complaints of violations of civil, political, social, economic and cultural rights as elaborated in the Convention. Optional Protocols must be separately signed and ratified by each State Party. It is possible to ratify an Optional Protocol without actually ratifying the main Convention. For example, the USA has ratified the Optional Protocol to the UNCRC on the Sale of Children, Child Prostitution and Child Pornography, and Armed Conflict but not the UNCRC itself.

**Person/child with a disability** – 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.

**Preamble** – the introductory paragraphs of a human rights treaty that explain the context for the treaty itself. The preamble is not, itself, legally binding.

**Progressive realisation** – this is a principle of international human rights law that applies only to economic, social and cultural rights but not to civil and political rights. States have an immediate responsibility to undertake their civil and political rights obligations (because the need to do so is urgent and/or because they cost very little to deliver). However, the concept of progressive realisation recognises that States with limited resources may be unable to fully implement their obligations to fulfil economic, social and cultural rights obligations immediately. They are, nevertheless, required to fulfil those obligations to the maximum extent possible within available resources, including where necessary seeking international cooperation. In other words, they are expected to ensure that all possible resources and measures are directed towards the full implementation of the obligations in the convention, and in every case certain core obligations must be met.

**Ratification** – the process of a country officially agreeing to be bound by a convention. Each country has its own rules and procedures about who can make that decision and what decision-making process should be used.

**Reasonable accommodation** – means necessary and appropriate modification and adjustments, where needed in a particular case, to ensure that people with disabilities have the enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms. These should not impose a disproportionate or undue burden.

**Reservations, understandings and declarations (sometimes known as RUDs)** – when a country decides to ratify a convention, it can choose to exempt itself from compliance with particular provisions it contains. This is known as a reservation. It can also make a statement (a declaration) as to how it will interpret a particular provision. RUDs are presented by a country at the same time that they submit their ratification of a convention. No reservation can be made that is incompatible with the object and purpose of the convention. For example, it would not be possible in the CRPD to make a reservation to the principle of non-discrimination or inclusion.

**Rights-based approach to development** – an approach to development that combines human rights, development work and social activism to promote justice, equality and freedom. It holds duty bearers to account for their obligations, empowers people to demand their rightful entitlements, promotes equity and challenges discrimination.

**Signatory** – by signing a convention, countries indicate their intention of becoming a party to the convention by ratification, but are not obligated to put its provisions into effect before ratification. However, they must not do anything that is contrary to the object and purpose of the convention.

**Social/cultural model of disability** – an approach to the issue of disability that, instead of focusing on the individual's physical or mental characteristics, looks at the interaction of the individual and society. The social/cultural model of disability proposes that the problems faced by people with disabilities are not the result of the person's impairment(s), but are instead the result of barriers in society. These barriers may be physical, attitudinal, legislative, informational or any other kind of barrier resulting from a society's or culture's failure to accommodate a person.

**Standard rules** – The Standard Rules on the Equalization of Opportunities for Persons with Disabilities were adopted in 1993 by the United Nations General Assembly. Although not a legally binding instrument, they were an instrument for policy-making and a basis for technical and economic cooperation. The Standard Rules consists of 22 rules addressing preconditions for equal participation, target areas for equal participation, implementation measures, and the monitoring mechanism. They cover all aspects of life of disabled persons.

**State Party** – a country that has ratified a convention, and is legally bound to comply with its provisions.

**Treaty** – see 'Convention'.

**Treaty monitoring body** – a committee of experts mandated to oversee and monitor the implementation of a human rights convention. Typically, a convention will indicate how large the committee will be, the criteria for selection of members, when and where the committee will meet, and what the committee is authorised to do in monitoring implementation. Many committees receive reports from governments describing what the country has done to implement its obligations under a convention. The committee will usually have an opportunity to ask questions of the States Party about the report, and then provide feedback in response to the report. Committees may also be mandated to issue general comments giving their authoritative interpretation of the convention. Some committees can receive complaints from individuals and/or groups concerned that a State Party is violating its obligations under the convention.

**United Nations (UN)** – this is an inter-governmental membership organisation that was founded in 1945 and has headquarters in New York and Geneva. The UN is dedicated to maintaining international peace and security;

developing friendly relations among nations; cooperating in solving international economic, social, cultural and humanitarian problems and in promoting respect for human rights and fundamental freedoms; and being a centre for harmonising the actions of nations in attaining these ends.

**United Nations Member State** – a country that has chosen to join the United Nations. To join the UN, a country must become a State Party to the UN Charter – this is an international convention with which UN Member States are legally obliged to comply. When the UN began in 1945 there were 51 Member States, but membership has grown

dramatically since then, and as of 2009, there are 192 UN Member States.

**Universal design** – means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design. Universal design does not exclude assistive devices for particular groups of people with disabilities where this is needed. For example, the use of Braille for blind people is still needed, although universal design could be employed to make public signs and symbols to accommodate the majority of the population.

**Part one**

**The development of  
rights for children  
with disabilities**

# I A brief introduction to human rights

## What are human rights?

Human rights are rights a person has because he or she is a human being. Human rights can also be defined as those basic needs without which people cannot live in dignity. If you violate a person's human rights, you are treating them as less than a human being. Human rights recognise and affirm that the human dignity of all people – and that includes all children – must be respected.

## The central features of human rights

- **Universality and inalienability:** All people everywhere in the world have human rights. An individual cannot voluntarily give them up. Nor can others take them away from him or her.
- **Indivisibility:** Human rights are indivisible. Civil, cultural, economic, political and social rights are all fundamental to the dignity of every human being. Consequently, they all have equal status as rights, and cannot be ranked in a hierarchical order.
- **Interdependence and interrelatedness:** The realisation of one right often depends, wholly or in part, upon the realisation of others. For example, the right to education for children with disabilities can only be fully achieved if other rights are also respected – non-discrimination, freedom from poverty, protection from violence.

- **Equality and non-discrimination:** All individuals are equal as human beings and are entitled to their human rights without discrimination of any kind.

## Where are human rights documented?

### International systems

Rights for every human being were elaborated in 1948 in the United Nations Universal Declaration of Human Rights (UDHR). Its 30 articles form a comprehensive statement covering economic, social, cultural, political and civil rights. It sets out the fundamental principle that “the inherent dignity and the equal and inalienable rights of all members of the human family are the foundation of freedom, justice, and peace in the world”. However, the UDHR is a statement of intent or a set of principles; it is not a legally binding document. Since 1948, therefore, the United Nations (UN) has used the UDHR as the foundation from which to develop a number of human rights treaties (also called conventions or covenants), which translate its principles into legally binding obligations on the countries that ratify them.

The first two human rights treaties were the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR), which were adopted by the UN

in 1966. Together with the UDHR, they make up what is known as the International Bill of Rights. Since then, a number of further treaties have been adopted to address the rights of specific groups of people, including women, children, migrant workers, racial minorities and people facing torture. The Convention on the Rights of Persons with Disabilities (CRPD) is the most recent treaty to be adopted.

## Regional systems

Some regions of the world have also developed systems for protecting human rights that serve to strengthen or complement the international system, for example:

- European Convention for the Protection of Human Rights and Fundamental Freedoms, 1950

- American Convention on Human Rights, 1978
- African Charter of Human and People's Rights, 1981
- African Charter on the Rights and Welfare of the Child, 1990.

## National systems

Individual countries also have constitutions and laws that guarantee and protect the rights of citizens, including children. These frameworks can serve to introduce international human rights into domestic law, or to set higher standards than those provided in the international treaties. The difference between national laws and human rights treaties is that the latter are universal – they apply to all people everywhere, regardless of their citizenship or where they live.

### Key human rights documents

- Universal Declaration of Human Rights, 1948
- International Covenant on Civil and Political Rights, 1966
- International Covenant on Economic, Social and Cultural Rights, 1966
- International Convention on the Elimination of all Forms of Racial Discrimination, 1966
- Convention on the Elimination of all Forms of Discrimination against Women, 1979
- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 1984
- Convention on the Rights of the Child, 1989
- Convention on the Rights of Migrant Workers and the Members of their Families, 1990
- Convention on the Protection of All Persons from Enforced or Involuntary Disappearances, 2006
- Convention on the Rights of Persons with Disabilities, 2006

For full texts of the treaties, go to:  
<http://www.ohchr.org/english/law/index.htm>

# 2 Historical overview of the rights of people with disabilities

## Growing awareness of disability as a human rights issue

International human rights law has been slow to recognise that disability is a human rights issue. Neither of the 1966 International Covenants, on civil and political rights and on economic, social and cultural rights (see page 12), contains any specific provision regarding the rights of disabled people, or explicit recognition of disability as a ground for protection against discrimination. However, both Covenants, in their discrimination articles, include in their lists of grounds the phrase “or other status”, which clearly extends to discrimination in respect of disability. Furthermore, in its General Comment on disability published in 1994, the Committee on Economic, Social and Cultural Rights (see ‘Treaty monitoring body’ in Glossary) has stated that “since the Covenant’s provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognised in the Covenant”.

In 1975, the United Nations (UN) General Assembly adopted the Declaration on the Rights of Disabled People – a document, however, with much less force than a convention. This asserts that disabled people have the same civil and political rights as other human beings. The year 1981 was designated as the International Year of Disabled Persons, and 1983–1994 was designated as the

Disability Decade. In 1984, the Human Rights Commission adopted a resolution that recommended that a Special Rapporteur be appointed to study the connection between serious violations of human rights and disability. Leandro Despouy was appointed as Special Rapporteur in August 1984 and his report, *Human Rights and Disabled Persons*, was published in 1993. Among his recommendations were proposals that national legislation should be adapted to international norms and guidelines, and that an international ombudsman should be appointed or that the UN Economic and Social Council (ECOSOC) should be given a special mandate to protect people with disabilities against violations of human rights. He also stressed that people with disabilities were at a disadvantage compared with other marginalised groups in that they did not have the protection of a single body of binding norms.

In 1993, the UN Standard Rules on Equalization of Opportunities for Persons with Disabilities were adopted by the UN General Assembly.<sup>9</sup> They have the status of a Declaration rather than a legally binding document, but as the resolution was adopted by consensus, without a vote, it is possible to argue that they are politically and morally binding on governments. They comprise 22 rules in total: four relating to preconditions for equal participation, eight relating to target areas for equalisation of opportunities and ten relating to

implementation measures. The UN Standard Rules are guidelines designed to enhance the rights of people with disabilities. A series of resolutions were adopted by the then Human Rights Commission stating that “any violation of the fundamental principle of equality or any discrimination or other negative differential treatment of persons with disabilities inconsistent with the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities is an infringement of the human rights of persons with disabilities”.

In summary, then, in the two-and-a-half decades up until the end of the 20th century, significant progress was made. Disability gradually became visible in the international human rights arena – due in large part to the effective and persistent lobbying undertaken by disabled people’s organisations. There was greater awareness of the abuses of disabled people’s rights and of the need for action to put a stop to these abuses. The first rung of the ladder had been reached. However, there was still insufficient protection within the international human

rights framework to address the problem and the violation of rights of people with disabilities continued.

## **Recognising children with disabilities as subjects of rights**

Children with disabilities suffer a double jeopardy. The formal absence, until the CRPD, of disability from the core human rights treaties has made their lives and difficulties invisible; even when action has been taken by the relevant international institutions to highlight the issue of disability, it has generally been taken from the perspective of adults not children. And while some areas of discrimination, abuse and neglect of rights are common to both adults and children, the failure to give explicit attention to children’s situation means that fundamental issues affecting them were neglected. This invisibility is exemplified in the Committee on Social, Economic and Cultural Rights General Comment on disability which, although it acknowledges the situation of

### **Key human rights documents relevant to disability (prior to the CRPD)**

#### **The International Bill of Rights:**

- Universal Declaration of Human Rights
- International Covenant on Economic, Social and Cultural Rights
- International Covenant on Civil and Political Rights

#### **Other United Nations and the International Labour Organization instruments dealing specifically with human rights and disability:**

- Declaration on the Rights of Mentally Retarded Persons, 1971
- Declaration on the Rights of Disabled Persons, 1975
- World Programme of Action concerning Disabled Persons, 1982
- Tallinn Guidelines for Action on Human Resources Development in the Field of Disability, 1990
- Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, 1991
- Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993

For full texts of the treaties, go to: <http://www.ohchr.org/english/law/index.htm>

children specifically in relation to education and the right to special protection, lacks a child-focused perspective on other important issues.<sup>10</sup> For example, it argues that absence of social security and income support should not be an excuse for institutionalisation. However, for children, the causes of institutionalisation may be different from those affecting adults – lack of practical support for parents, rejection based on prejudice and ignorance, the presumption that it is in the child’s best interests – none of which is dealt with in the General Comment. Moreover, there is no mention of the widespread use of humiliating, degrading and violent treatment and punishment in institutions or of children’s right to play and to participate in decisions that affect them.

In this context, the UN Convention on the Rights of the Child (UNCRC), adopted by the General Assembly in 1989, represented a major step forward. Not only does it place the issue of both children and disability in the arena of international human rights law for the first time, but it does so in the context of both civil and political rights, and economic, social and cultural rights.

The 1990s saw further developments. The UNCRC has been ratified by 193 states; the only member states of the UN that have failed to do so are the USA and Somalia. The Special Rapporteur recognised that the UN Standard Rules were inadequate for children, observing that “the child aspect and the gender perspective are vague in the text of the Rules”, and he suggested that both should receive more attention in future implementation efforts. In 1997, the Economic and Social Council adopted a resolution on ‘Children with disabilities’ that recognised the need for special attention to be directed towards children with disabilities and their families or other carers. It requested the Special Rapporteur “to pay special attention to the situation of children with disabilities, to pursue close working relations with the Committee on the Rights of the Child in its monitoring role

with respect to the UN Convention on the Rights of the Child, and to include in his report to the Commission for Social Development at its 38th session his findings, views, observations and recommendations on children with disabilities”. The resolution also urged governments to ensure, in accordance with rule 6 of the Standard Rules, that children with disabilities have equal access to education and that their education is an integral part of the educational system.<sup>11</sup>

In 2000, the then Commission on Human Rights in Geneva (which has now been replaced by the Human Rights Council) adopted a general resolution on children, which reaffirmed, among many other issues, the obligations on States to ensure the rights of the child without discrimination of any kind. In the same year, a Human Rights Commission resolution on disabilities was passed, urging governments to implement the Standards Rules with particular regard for the needs of, among others, children.<sup>12</sup>

## **Implications of the UN Convention on the Rights of the Child**

The UNCRC provides a holistic framework of comprehensive and binding principles which should underpin the treatment of children throughout the world. Its significance cannot be overstated. It establishes a set of universal minimum standards of entitlement for all. It recognises children as subjects of rights and insists on respect for children as actors in the exercise of their rights, and participants in all matters affecting them. It challenges the traditional perception and status of children as lesser individuals than adults. It provides the tools with which to analyse the situation of children, and the norms against which law, policy and practice must be measured. It establishes an international body for monitoring implementation: the Committee on the Rights of the Child. It insists on the

equal rights of all children. Governments' actions or inaction in respect of their children can now be scrutinised publicly within the international community.

All the rights in the UNCRC extend to all children under 18 years. However, it introduces specific rights for children with disabilities for the first time in international human rights law. **Article 2**, which deals with the right to non-discrimination, includes disability as a specific ground for protection against discrimination.

In other words, the Convention recognises that disability is a human rights issue. In addition, **Article 23** explicitly addresses the situation of children with disabilities.

The obligation to give explicit attention to the rights of children with disabilities has served to highlight the extent to which they are substantially neglected – and indeed, violated – at many levels in countries throughout the world. Initially, however, progress on implementation of these rights was slow. In a

### **Article 23 of the UNCRC**

1. Governments recognise 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. Governments recognise 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. Recognising 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 or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.
4. Governments 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 children with disabilities, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling governments to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

report to the former Commission on Human Rights Sub-Commission on Prevention of Discrimination and Protection of Minorities in February 1996, the Committee on the Rights of the Child summarised the general concerns it had identified from its examination of governments' reports, taking account of the obligations associated with Article 23, the general principles of the Convention, and the obligation on governments to undertake all appropriate measures to implement its provisions. Its findings were not encouraging:

“A first matter of concern is that some societies are not sufficiently sensitive to the needs and situation of children with disabilities, in the light of article 2 of the Convention. The Committee is preoccupied by the widespread discriminatory attitudes towards those children. Strategies and educational programmes, along with the adequate dissemination of information, should be undertaken to avoid certain prejudices which affect children with disabilities negatively...

“The Committee recognizes the prevalence of certain negative attitudes which hamper the implementation of the rights of children with disabilities with regard to article 23, such as isolation from the rest of society. The promotion of their rights should be further advanced through, for instance, support to parents' organizations and to community-based services and a sustained programme for moving children from institutions to a good family environment.

“The Committee is negatively impressed by the fact that some children with disabilities do not have adequate access to health and social care services and it expresses concern over the low number of children with disabilities enrolled in schools, which might reflect an insufficient attention to their specific needs. More protection should be offered them, including the possibility, through education, of integrating properly

into society and participating actively in family life. Efforts for the early detection of the incidence of handicap should be made.

“Budgetary reductions have also affected children with disabilities who are particularly disadvantaged in their access to adequate health and educational facilities. The Committee urges countries to take all the necessary steps to minimize the negative impact of the structural adjustment policies on the situation of children with disabilities. The Committee recognizes, in the light of article 4, the priority of allocating the maximum extent of the available resources to protect these children.

“International assistance and the exchange of appropriate information will also be needed to address more effectively the challenge of improving the situation of children with disabilities, in conformity with article 23, paragraph 4 of the Convention.”<sup>13</sup>

In 1997, in recognition of the need to gain a greater understanding of the situation of these children, the Committee on the Rights of the Child held a Day of General Discussion on the rights of children with disabilities at which it was recognised that “their plight rarely figured high on the national or international agenda and they tended to remain invisible”. Since then, the Committee has focused more consistently on the situation of children with disabilities in its examination of reports by governments and has drawn the attention of States to the Standard Rules.

In addition, the Committee agreed to produce a General Comment on children with disabilities, which would elaborate how governments are expected to implement the UNCRC in respect of this group of children. A draft produced by the Committee in 2006 was discussed in August that year at a meeting in New York of up to 40 representatives from disability organisations, before being finalised and adopted by the Committee in 2007.<sup>14</sup>

## Summary

Progress has been made but mainly at the legal level. The UNCRC has affirmed the right of children with disabilities to protection from discrimination, and to the provision of necessary services. The General Comment has highlighted the detailed obligations on governments necessary to ensure its implementation. Despite this, the scale and

severity of human rights abuses against children with disabilities have not been reduced.

Although the Committee on the Rights of the Child does now give much greater scrutiny to the rights of children with disabilities, they remain largely invisible, hidden within families or institutions, and vulnerable to the neglect of their economic, social, cultural, civil and political rights.

# 3 Development of the UN Convention on the Rights of Persons with Disabilities (CRPD)

The continued experience of people with disabilities as ‘objects of welfare’ rather than subjects of rights contributed to further pressure from the disability community for the development of a new human rights treaty to ensure that people with disabilities were able to enjoy their rights on the same basis as others.

## The timeline

Advocacy from the disability community gave rise to the following developments:

- In 2001, Mexico proposed that the United Nations (UN) General Assembly consider opening negotiations for a Convention on the rights of persons with disabilities.
- After debate in the Third Committee of the General Assembly, a resolution (no. 56/115) to this end was adopted on 19 December 2001. The UN agreed to set up an Ad Hoc Committee to consider proposals for the text of a Convention to address the rights of people with disabilities. Its membership was open to all UN Member States and observers.
- At its first two sessions, in 2002 and 2003, the Committee considered the possibility of drafting an international instrument on the rights of persons with disabilities,

and discussed the type of instrument and possible elements to be included. At the second session, it established a working group to prepare a draft text of a Convention.

- The Working Group, composed of governments, non-governmental organisation (NGO) representatives, and representatives from national human rights institutions (NHRIs), met in January 2004 and drafted an initial text for negotiation.
- At its subsequent sessions, the Ad Hoc Committee discussed and negotiated this text, which was finalised on 26 August 2006.
- On 13 December 2006, the UN General Assembly adopted the text of the CRPD and its optional protocol.
- The CRPD opened for signature and ratification on 30 March 2007.
- The CRPD entered into force on 3 May 2008, after 20 States had ratified.

## A paradigm shift

Throughout the drafting process of the Convention, the Chair of the Ad Hoc Committee stressed that what was needed was a ‘paradigm shift’ in the attitudes and treatment of people with disabilities – from seeing them as objects of charity to seeing them as individuals

with human rights. This necessitates recognition that people with physical, psychosocial, intellectual or sensory impairments face many barriers that prevent them from full and effective participation in society on an equal basis with others. Those physical, linguistic, social and cultural barriers must be removed. The Convention recognises that a change of attitude in society is necessary if disabled people are to achieve equal status, and it includes a specific article on awareness-raising to promote respect for the rights and dignity of people with disabilities. The Convention in its entirety is dedicated to achieving that change. It will finally ensure that countries will no longer be allowed to relegate people with disabilities to the margins of society. Governments that ratify it will be legally bound to treat them as subjects of the law with clearly defined human rights.

### **Process as important as outcome**

In terms of building the momentum for the paradigm shift, the process of drafting the Convention was as important as the text itself. The pressure for the Convention came from the disability movement, and they were actively involved throughout the entire process. The sessions of the Ad Hoc Committee were notable for the significant level of engagement on the part of the disability community, which organised itself through an informal network known as the International Disability Caucus (IDC), a coalition of 70 international and national disabled people's and allied organisations around the world. It played a crucial role, sharing knowledge and life experiences, drafting amendments, analysing the debates, lobbying government delegations, speaking from the floor, organising meetings, providing information and technical expertise, and presenting a unified and powerful voice to ensure the best possible final text. People with disabilities were represented through the IDC but also, increasingly over the four to five

years, through representation on government delegations. Indeed, such was their contribution that the Chair of the Ad Hoc Committee, Ambassador Don McKay, observed that "at least 80 per cent of this Convention has been drafted and developed by disabled people's organisations".

The involvement of people with disabilities, including children, as key actors in the development of the Convention was transforming, and a learning experience for all involved. Government delegates who had no previous experience of the issues, let alone of working directly with people with disabilities, were confronted with profound challenges to their stereotypes and prejudices. The very presence and competence of the disability organisations confounded traditional perceptions of disabled people, including disabled children, as victims in need of care, protection and support. It forced a recognition that these were people entitled to respect for their rights and able to articulate and advocate forcefully for that respect.

### **The significance of the Convention**

All human rights already apply to all people, irrespective of disability. Given this, the main intention of the CRPD was not to establish specific new human rights for people with disabilities. Rather, its significance lies in the fact that it is designed to ensure that these existing rights are made a reality. This treaty introduces new obligations to overcome barriers, and measures to ensure that people with disabilities are acknowledged as subjects of rights, entitled to respect on an equal footing with all other people. More specifically it:

- clarifies human rights principles in the context of people with disabilities
- provides an authoritative model for governments to use in shaping national law and policies

- creates more effective mechanisms for monitoring the rights of people with disabilities
- establishes international standards regarding the rights and freedoms of people with disabilities
- establishes common bases for greater participation and self-sufficiency of people with disabilities worldwide
- provides for consultation with persons with disabilities and their representative organisations, underlining the disability organisations' motto, "Nothing about us without us".

## **The need for explicit recognition of children within the CRPD**

As noted above, the UN Convention on the Rights of the Child provides a foundation of principles and detailed provisions for the rights of all children, and the first mention in an international treaty of the rights of children with disabilities. It was important, therefore, that the new Convention should build on this achievement and incorporate specific provisions on the issues facing children with disabilities.

## **Children are not the same as adults**

Although many of the experiences of adults with disabilities and children with disabilities are similar, they are not the same. Equally, although parents and children share many concerns, their interests are not the same. It is not appropriate, therefore, that the rights of children are simply assumed to be the same as those of adults with disabilities or of those of their parents. In order to ensure that the rights of children with disabilities are addressed appropriately within the new Convention, it was imperative that their different perspectives were reflected and made explicit in the text of the new convention.

## **Children lack autonomy**

Children in all societies have a different legal status from adults. For most adults, there is a presumption of autonomy that is not presumed for all children. Autonomy involves the right of an individual to self-determination, including for example, the right to informed consent for treatment, or to refuse treatment, to parent, to marry and engage in consensual sexual relationships or to vote. A central principle in the CRPD is that all people with disabilities shall be granted equal respect for their autonomy. However, it is not possible to argue for autonomy for all children, with or without disabilities. Rather, there needs to be recognition, as in Article 5 of the UNCRC, of the responsibility of parents and other carers to provide direction and guidance, "in accordance with the evolving capacities of the child", in the exercise by children of their rights. In other words, as children acquire the competence to exercise rights for themselves, they are entitled to do so. Without addressing this issue, the Convention's focus on autonomy would have implied that some – or perhaps all – children are excluded from its provisions.

## **Children have the right to additional protections**

Because many children lack autonomy, and are more vulnerable as a consequence of their youth, they are entitled to additional protections. The nature of these protections are detailed in the UNCRC. However, many of the rights in the UNCRC are inadequately understood or implemented for children with disabilities. The CRPD, therefore, needed to include additional measures to ensure their realisation. For example, Article 19 of the UN Convention on the Rights of the Child provides a right to protection from all forms of violence. Children with disabilities experience specific and significant difficulties in seeking redress for violence. It was important therefore that the CRPD introduced an obligation on States to

ensure that all relevant complaints and redress procedures are adapted for and accessible to children with disabilities.

### **Children, too, have the right to be heard**

The Convention places emphasis on the obligation of governments to consult with and involve disabled people and their organisations in the development of policies and legislation. It was important to make it explicit that this obligation extends to consultation with children as well as adults. Children's experiences and concerns cannot be adequately represented by adults. They have their own unique expertise and perspective to contribute. Without an obligation to consult children, children with disabilities would again be marginalised and denied a voice. It is not sufficient to argue that children are implicitly included in these provisions. Experience demonstrates clearly that without an explicit entitlement, children will not be listened to.

### **Children with disabilities are denied visibility**

When children's rights are considered, children with disabilities tend to be forgotten. When the rights of people with disabilities

are considered, children with disabilities tend to be forgotten. Their rights therefore are at risk of being marginalised. An analysis of the government reports and the Concluding Observations of the Committee on the Rights of the Child undertaken between 2000 and 2003 found that governments consistently failed to give appropriate recognition to the violations of disabled children's rights.<sup>15</sup> They only addressed those rights covered in Article 23, dealing primarily with services for children with disabilities. For example, rights to participation, information, an adequate standard of living, play or protection from violence were never raised in respect of children with disabilities. In other words, disabled children were disregarded, except where they were expressly mentioned in the Convention.

Without an explicit recognition of the issues facing children with disabilities, the CRPD would be interpreted only in respect of adults. In order to ensure that the rights of children with disabilities were given appropriate consideration, it was important, therefore, that it made children visible by explicitly stating, where appropriate, that its provisions extended to them.

## Action taken by Save the Children to ensure that the CRPD addressed the rights of children with disabilities

Working through the International Disability Caucus (IDC), Save the Children coordinated action to ensure that the CRPD addressed the rights of children with disabilities.

### Drafting, briefing and lobbying

Repeated analysis of the Working Group draft texts were undertaken to assess where amendments were needed in order to better reflect the situation of children with disabilities. Once agreed through the IDC, briefings were written to support these proposed amendments and circulated to government delegations. A 'twin-track' approach was adopted to ensure that the interests of children with disabilities were properly represented. The aim was, on one hand, to retain a specific article on children with disabilities, establishing the core principles relating to children that would inform implementation of the Convention. On the other, it was to secure the inclusion of explicit references to issues of particular or unique concern to children in all other relevant articles. These included, for example, articles in relation to family life, abandonment, play and birth registration.

### Involving the Committee on the Rights of the Child

Given the view expressed by some government delegations that the inclusion of specific provisions on children would potentially undermine their rights in the UNCRC, Jaap Doek, then Chair of the Committee on the Rights of the Child, agreed to make a presentation to the Ad Hoc Committee in August 2005, emphasising that the proposed amendments would strengthen rather than

undermine existing rights. He argued that the CRPD would serve to elaborate the interpretation of the UNCRC for children with disabilities.

### Involving children with disabilities

Children and young people with disabilities also played an important role. In January 2006, two children from Bangladesh, and two young people each from China and the UK, made a presentation to the Ad Hoc Committee setting out their demands, including the right to inclusive education, to be consulted, to support for families and to non-discrimination. In a widely circulated written statement, they also highlighted the need for recognition of the importance of ending institutionalisation, challenging violence and abuse, ensuring access to services, opportunities for friendships with peers and access to information.

Their participation in the process was important, serving to challenge the argument for excluding specific provisions on children:

- It brought home to the delegations the fact that children with disabilities are a distinct constituency who have a right to recognition, yet who, to date, had been given very little consideration.
- It affirmed that children with disabilities can be effective advocates for their own rights and are entitled to be involved in decisions that affect them.
- It affirmed that adults have lessons to learn from children with disabilities.
- It highlighted the principal concerns faced by children with disabilities, many of which required specific additional provisions in the draft text.

# 4 Key provisions of the CRPD

## Key obligations on specific human rights

The CRPD introduces obligations on countries to take measures to protect the rights of people with disabilities, as set out in the Preamble and the following articles.

### Preamble

Outline of why the Convention is needed and of the other human rights instruments that helped form the basis for this Convention.

### Article 1 Purpose

What the Convention seeks to achieve: the promotion, protection and full and equal enjoyment of all human rights by people with disabilities.

### Article 2 Definitions

The meaning of some terms used for this Convention.

### Article 3 General principles

The fundamental concepts that should guide interpretation of the Convention obligations.

### Article 5 Equality and non-discrimination

People with disabilities must be treated fairly, which may require proactive measures.

### Article 6 Women with disabilities

Rights of women with disabilities and the need to address the fact that women and girls are subject to multiple discrimination.

### Article 7 Children with disabilities

Rights of children with disabilities, including the principle of best interests of the child and the right of the child to be heard.

### Article 8 Awareness-raising

Measures that should be taken to highlight disability rights in society.

### Article 9 Accessibility

Ways in which communications and information systems, transport, buildings and other structures can be used, entered or reached.

### Article 10 Right to life

People with disabilities have the same right as others to live without interference.

### Article 11 Situations of risk and humanitarian emergencies

A country has the obligation to ensure the protection of people with disabilities in situations such as armed conflict, humanitarian emergencies and natural disasters.

**Article 12 Equal recognition before the law**

People with disabilities have the same standing as others in exercising their legal capacity, with support if necessary.

**Article 13 Access to justice**

People with disabilities have the same opportunity as others to access to justice, and must be provided with the necessary support to enable them to do so.

**Article 14 Liberty and security of the person**

People with disabilities enjoy the same freedom as others to act. Moreover, they enjoy the same level of protection or safety against threats to human rights, such as arbitrary detention, physical harm and food deprivation.

**Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment**

A country must prevent any acts by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person. There is also a prohibition on involuntary medical or scientific experimentation.

**Article 16 Freedom from exploitation, violence and abuse**

People with disabilities must be protected from physical, sexual and psychological mistreatment. If mistreatment occurs, then all measures need to be taken to ensure recovery.

**Article 17 Protecting the integrity of the person**

The physical and mental integrity of people with disabilities must be respected.

**Article 18 Liberty of movement and nationality**

People with disabilities have the same freedom as others to change their country or home,

cross borders and obtain citizenship. Children with disabilities must be registered at birth.

**Article 19 Living independently and being included in the community**

A country has the obligation to ensure that people with disabilities can choose where they live, and to provide the necessary support to enable them to live within the community.

**Article 20 Personal mobility**

People with disabilities shall have necessary assistive devices, technologies and mobility aids to enable them to be mobile.

**Article 21 Freedom of expression and opinion, and access to information**

A country will guarantee that people with disabilities enjoy the ability to share thoughts, beliefs, feelings or personality, through verbal or non-verbal means. This obligation also extends to receiving information in accessible modes and formats of their choice. Sign language should be recognised and promoted.

**Article 22 Respect for privacy**

The privacy of people with disabilities must be respected, and they have the right to protection against interference with their privacy.

**Article 23 Respect for the home and the family**

The choices of people with disabilities regarding where they live, how they live, and with whom they live, must be respected. A country must provide support for families to help keep them together and prevent rejection of children with disabilities.

**Article 24 Education**

Equal and inclusive access to the lifelong learning process is guaranteed, including in primary, secondary and tertiary education, and vocational institutions. Necessary measures to

facilitate access should be undertaken. No one must be excluded on the basis of disability. Children have the right of access to inclusive education with the obligation on duty-bearers to provide the support required within the general education system. Training of professionals is essential, as well as hiring teachers with disabilities.

### **Article 25 Health**

People with disabilities have equal access to the same standard of healthcare and healthcare services, including health insurance, to ensure their physical, mental and social wellbeing.

### **Article 26 Habilitation and rehabilitation**

States have an obligation to ensure that people with disabilities are equipped with the means to achieve the maximum possible independence and participation in life.

### **Article 27 Work and employment**

People with disabilities have equal access to a means of livelihood. In addition, countries have

the obligation to promote livelihood opportunities.

### **Article 28 Adequate standard of living and social protection**

People with disabilities and their families are guaranteed access to food, shelter, clothing and drinking water. In addition, they have the same access as others to governmental safety nets.

### **Article 29 Participation in political and public life**

People with disabilities are entitled to be represented or participate in government and other civic activities.

### **Article 30 Participation in cultural life, recreation, leisure and sport**

People with disabilities have equal access to play, relaxation, amusement and physical pastimes.

See also Child-Friendly Text UN Disability Convention. [http://www.unicef.org/Child\\_friendly\\_CRPD.doc](http://www.unicef.org/Child_friendly_CRPD.doc)

## **Specific provisions for children with disabilities**

The CRPD as a whole applies to children with disabilities. However, the specific provisions in the text which apply to children are as follows:

### **The preamble**

Recognises that children with disabilities should have full enjoyment of all human rights on an equal basis with others.

### **Article 7 Children with disabilities**

Introduces obligations to ensure the enjoyment of all human rights and fundamental freedoms on an equal basis with other children, to ensure that the best interests of the child is a primary consideration, and to provide disability and age-appropriate assistance to ensure that children with disabilities are able to realise the right to their express views on all matters of concern to them and have them taken seriously in accordance with age and maturity.

*continued opposite*

## Specific provisions for children with disabilities

*continued*

A number of other articles include specific measures to address the situation of children with disabilities:

- **Article 3 – General principles:** There must be respect for the evolving capacities of children and their right to preserve their identities.
- **Article 4 – General obligations:** Children with disabilities must be consulted when governments are developing and implementing legislation and policies that concern them.
- **Article 13 – Access to justice:** Age-appropriate measures must be introduced to ensure that children with disabilities have access to justice.
- **Article 16 – Freedom from exploitation, violence and abuse:** Measures must be taken to provide age-sensitive assistance to prevent exploitation, violence and abuse; age-, gender- and disability-sensitive protection and rehabilitation services; and child-focused legislation to ensure that exploitation, violence and abuse is identified and investigated.
- **Article 18 – Liberty of movement and nationality:** Measures must be taken to ensure that children with disabilities are registered immediately after birth.
- **Article 23 – Respect for home and the family:** Children with disabilities are entitled to retain their fertility, and therefore forced sterilisation is prohibited. Children with disabilities have equal rights with respect to family life and governments have obligations to provide services and support to families to prevent abandonment, concealment and segregation. In addition, children with disabilities must not be separated from parents unless this is in their best interests and never on the basis of disability. Where parents are unable to care for children, efforts must be made to provide alternative care within the wider family or within the community in a family setting.
- **Article 24 – Right to education:** Education at all levels must be inclusive and children with disabilities have an equal entitlement to general education. Inclusive education requires provision of all necessary support and technical aids, including respect for linguistic identity, and facilitating the learning of Braille, orientation and mobility skills, and training of teachers.
- **Article 30 – Participation in cultural life, recreation leisure and sport:** Children with disabilities must be provided with equal access to participation in play, recreation, and leisure and sporting activities, including in schools.

## **Procedures for signing and ratification of the Convention**

The Convention addresses how countries can commit themselves to implementing the Convention.

### **Article 41 Depositary**

Ratifications are deposited with the UN Secretary-General.

### **Article 42 Signature**

Countries could sign the Convention as from 30 March 2007.

### **Article 43 Consent to be bound**

Once the Convention comes into force, countries or regional organisations can still become members by signalling their consent to be bound.

### **Article 45 Entry into force**

The Convention is operative one month after 20 ratifications have been deposited. This happened on 3 May 2008.

### **Article 46 Reservations**

A country is allowed to state that it does not wish to be bound by certain aspects of the Convention, unless this is inconsistent with the Convention's object and purpose.

## **Measures of implementation**

In addition to introducing specific obligations on governments to take action to protect the rights of people with disabilities, the Convention also requires governments to take general measures to create the framework for implementation.

### **Article 4 General obligations**

Governments are required to adopt broad measures to ensure implementation of the Convention including legislative measures.

### **Article 31 Statistics and data collection**

A country is obligated to gather disability-related information to assist in the Convention's implementation. Any information-gathering must comply with ethical standards.

### **Article 32 International cooperation**

Bilateral and multilateral partnerships are essential to support the Convention's implementation. Donor countries should ensure that a disability perspective is included in development aid policy and practice.

### **Article 33 National implementation and monitoring**

Countries must designate focal points within the government with responsibility for the implementation of the Convention. They should give consideration to creating a coordinating mechanism across government. Independent institutions for promoting, protecting and monitoring the Convention should be established, and civil society organisations, including organisations of people with disabilities, should be involved in monitoring the Convention.

## International monitoring

The CRPD, in common with other international human rights treaties, introduces measures to provide a process for international monitoring of countries' progress in implementing their obligations under the Convention.

### **Article 34 Committee on the rights of persons with disabilities**

A 12-member committee of independent experts (Committee) monitors how countries implement the Convention. (The number of experts will go up to 18 when there are 60 ratifications.) The members should come from different regions, and there should be both disability and balanced gender representation.

### **Article 35 Reports by governments**

Countries must provide periodic information to the Committee on how they are complying with their Convention obligations.

### **Article 36 Consideration of reports**

The Committee reviews the information, provides feedback to the country and makes its suggestions public. If a country does not provide information, then the Committee can provide recommendations based on other reliable information.

### **Article 37 Cooperation between governments and the Committee**

Countries agree to collaborate with the Committee. Partnerships at multilateral and bilateral levels should be promoted.

## Miscellaneous provisions

### **Article 47 Amendments**

The Convention can be changed if two-thirds of countries party to the Convention agree.

### **Article 48 Denunciation**

A country can decide to no longer be party to the CRPD by giving written notice.

### **Article 49 Accessible format**

The Convention should be available in accessible formats, such as Braille.

### **Article 50 Authentic texts**

English, Chinese, Russian, Arabic, Spanish and French are considered official language texts.

## Individual petitions

In addition to the Convention, a separate but linked optional protocol has been adopted that provides an individual complaint mechanism for anyone who cannot achieve justice, in relation to the CRPD, at national level. The Committee on the Rights of Persons with Disabilities may also carry out inquiries – visiting a State Party if there are reliable reports of grave or systematic violations in that country. Once the Convention has entered into force, the Optional Protocol enters into force one month after ten ratifications of the Protocol have been deposited.

## **Individual or group communications (Optional Protocol to the CRPD)**

The Optional Protocol (OP) enables individuals or groups who consider that their rights under the CRPD have been violated, to make a complaint to the Committee on the Rights of Persons with Disabilities (this is known as a 'communication'). When governments ratify the CRPD, they can decide whether or not also to ratify the OP. Note that individuals or groups can only make a communication to the Committee if their government has ratified the Protocol.

**Making a communication:** Individuals or groups can make a communication only if the abuse complained of represents the violation of a right under the CRPD. They must also have exhausted all possible domestic remedies, through either local or national complaints mechanisms, the courts or administrative hearings. The Committee will not hear a communication if it considers that it is not properly substantiated or if it is anonymous. The violation must also have taken place after the OP has entered into force for the relevant State Party.

**Consideration of the communication:** As soon as it receives a communication, the Committee must inform the State Party, which is required, within six months, to provide a written explanation or statement, explaining its position and detailing any remedies it might have undertaken. In a situation of acute violation, the Committee may also request that urgent action is taken to protect the victim, pending a final determination on the communication. Once the Committee has all the information it needs, it will hold a closed meeting to consider the case. It will then forward any suggestions or recommendations to the State Party concerned, as well as to the applicant.

**Finding of a violation:** If there has been a finding that a violation has occurred, the State Party will be asked to cooperate in the examination of the information and submit their observations. Depending on the severity or complexity of the case, the Committee may appoint one or more members to conduct an inquiry, which may involve a visit to the country involved. The findings will then be sent to the State Party, which is expected to submit a reply within six months, together with any action it has taken in response to the inquiry.

*continued opposite*

## **Inquiries**

The Optional Protocol also introduces a provision whereby the Committee on the Rights of Persons with Disabilities, where it receives reliable information indicating that a State Party has committed grave or systematic violations of the rights in the CRPD, has the authority to invite the State Party to cooperate in the examination of the information, and submit its observations. Following this submission, the following action can take place:

- The Committee may designate a number of its members to conduct an inquiry, and report to the Committee. Such an inquiry may necessitate a visit to the country concerned.
- It will inform the State Party of its findings, comments and recommendations.
- The State Party is then required, within six months, to submit its observations to the Committee.

It is important to note that such inquiries must be conducted confidentially.

**Part two**

**Implementing the  
rights of children  
with disabilities**

# 5 Responsibility for implementation of the CRPD

*“You know, there are rules and laws and regulations set up by the UN on how disabled people should be treated. There are conferences, meetings, etc held where there are decisions made. WHERE DOES ALL THIS END UP? Let this all not end up on paper as the previous have. Let it go through to the people, which I think is not a very difficult job. Let the disabled people know their rights through whatever you come up with so that they can fight for their rights.”*

(Girl, 19, Somalia, quoted on UNICEF’s ‘Voices of Youth’ website)

When States ratify a convention, they accept obligations to implement it. In other words, they are duty bearers. Implementation is the process by which they take action to ensure that all the rights in the Convention are realised for everyone for whom it is applicable. In the case of the United Nations Convention on the Rights of the Child (UNCRC), this means all children under 18 years of age, and in the case of the Convention on the Rights of Persons with Disabilities (CRPD), it means all people with disabilities, including children. However, if the rights of children with disabilities are to be implemented fully, all sectors of society, including children themselves, need to be engaged.

## The obligations of governments

The CRPD includes a number of provisions that set out what governments are required to do in order to implement the rights it contains. The UNCRC also includes obligations to take action to implement its provisions. These obligations have been described by the Committee on the Rights of the Child as the “General measures of implementation”, and they have been elaborated in a General Comment published in 2003.<sup>16</sup> This provides useful guidance on how to apply the obligations on implementation included in the CRPD. The obligations can be clustered under ten broad headings:

1. Implement the CRPD to the maximum extent of available resources.
2. Adopt legislation to protect rights and end discrimination.
3. Introduce coordination across government.
4. Ensure that both private and public sectors respect the rights of children with disabilities.
5. Involve children with disabilities in the development, implementation and monitoring of laws, policies and decision-making processes.
6. Establish independent human rights institutions.
7. Make sure the CRPD is known.
8. Undertake research.
9. Promote international cooperation.
10. Report to the UN Committee on the Rights of Persons with Disabilities.

## Reasons why governments fail to meet their obligations

Advocacy groups highlight the following common obstacles to getting governments to meet their obligations to children with disabilities:

- lack of baseline information and research
- lack of legislation and policies
- failure to implement legislation and policies
- lack of budgetary provision
- low priority within government
- agendas driven by donors
- lack of capacity among non-governmental organisations (NGOs)
- lack of training centres to build capacity
- lack of information on disability issues
- failure to sensitise public officials and the wider public
- lack of trained officials
- failure to involve children in policy-making
- lack of coordination within government and between government and civil society.

### The overarching duties

Implicit in the Convention are three distinct duties:

- **The obligation to respect:** Governments must refrain from interfering with the enjoyment of the rights of people with disabilities. For example, school authorities must not exclude a student with a disability from education on the basis of disability.
- **The obligation to protect:** Governments must prevent violations of these rights by third parties. For example, the state must ensure that private schools do not discriminate against a person with a disability in their education programmes.
- **The obligation to fulfil:** Governments must take appropriate legislative, administrative, budgetary, judicial and other actions towards the full realisation of these rights. For example, the state must ensure that free secondary education is progressively available to all, including people with disabilities.

## **I Implement the CRPD to the maximum extent of available resources**

When states ratify the CRPD, they take on obligations under international law to adopt all appropriate legislative, administrative and other measures to implement it. However, there is a distinction between civil and political rights on the one hand, and economic, social and cultural rights on the other. It is widely recognised in international law that lack of resources in developing countries means it is not always possible to fully implement economic, social and cultural rights immediately. A concept of 'progressive realisation' has therefore been introduced. Governments are required to take measures to the maximum extent of their available resources, and where needed within the framework of international cooperation, to achieve the progressive implementation of those rights.

This concept was first introduced in the International Covenant on Economic, Social and Cultural Rights, and is also included in the

UNCRC and in Article 4(2) of the CRPD. However, it does not provide governments with the possibility of 'opting out' of responsibility for the implementation of these rights. Both the Committee on Economic, Social and Cultural Rights and the Committee on the Rights of the Child have stressed that governments have to be able to demonstrate that they have done everything they can, and diverted all possible resources to the realisation of economic, social and cultural rights, including, where necessary, through seeking international cooperation.<sup>17</sup>

In addition, governments are required to fulfil at least the very basic levels of each of the rights in the relevant Conventions. Thus, where numbers of individuals are deprived of essential primary healthcare, basic housing, essential foodstuffs or the most basic forms of education, a government would not be deemed to be meeting its core obligations.

In 2007, the Committee on the Rights of the Child held a Day of General Discussion on Resources for the Rights of the Child. It made a number of recommendations as to how

## **Identifying concrete actions in Mozambique towards implementation of the Convention<sup>18</sup>**

Mozambique signed the Convention on the Rights of Persons with Disabilities on 30 March 2007 and is in the process of ratification. The World Health Organization (WHO), in collaboration with the Mozambican Youth and Disability Association (AJODEMO) and Handicap International, organised a workshop on the Convention that was opened by the Vice-Minister of the Ministry of Women

and Social Affairs. Participants made recommendations and put forward concrete ideas on how to advance the implementation of the Convention specifically in relation to political rights, right to education, access to cultural life (including sports), health and rehabilitation, and situations of emergency. A brochure outlining the provisions of the Convention was made available in Portuguese.

resources should be mobilised to ensure the realisation of the rights of children, including children with disabilities.<sup>19</sup>

## **2 Adopt legislation to protect rights and end discrimination**

*“We have already learnt from experience, in countries that have implemented legislation related to disability, that change comes more rapidly when laws are in place.”<sup>20</sup>*

Article 4(1)(a) of the CRPD requires governments to introduce laws to implement the Convention. Governments need to undertake a comprehensive review of all legislation to ensure that it complies with the provisions of the Convention. Ideally, this should not happen only at the time of ratifying the Convention; there should be a continuing process of ‘disability-proofing’ all proposed legislation to check that it does not discriminate either directly or indirectly against people with disabilities. All government departments need to be involved in reviews of legislation relevant to their area of work, but it is also a good idea for independent bodies to be involved, such as parliamentary committees, national human rights institutions, academics, disabled people’s organisations and children with disabilities.

Article 4(1)(b) requires that legislative measures are also taken, where appropriate, to modify or abolish any existing laws, regulations, customs or practices that constitute discrimination against people with disabilities. These might include, for example, refusing children with disabilities access to festivals, or their right to give evidence in court or to enrol for higher education.

It is also important to ensure that the provisions of the Convention are fully incorporated into the domestic legal system. Only when this happens can children challenge violations of their rights through the courts. How it is done will depend on the legal system within the particular country. In some countries, international law has what is known as ‘self-executing force’. This means it automatically becomes law once the Convention is ratified, and individuals or groups can go to court for redress if its provisions are violated or not implemented. In other legal systems, it is necessary for governments to incorporate the Convention into national law, either by a single act or by amending all relevant legislation to bring it into line with the Convention provisions. It is only when this has been carried out that people can use the courts to protect their rights.

## Illustrative examples of constitutional guarantees of non-discrimination<sup>21</sup>

- Section 15 of the 1982 **Canadian Charter of Fundamental Rights and Freedoms** stipulates: “Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.”
- Article 3 of the **Constitution of the People’s Republic of China** states that “disabled people enjoy the same rights as other citizens in respect of political, cultural and social aspects, as well as family life” and that “it is forbidden to discriminate against, insult or harass disabled persons”.
- Article 3 of the **Basic Law of the Federal Republic of Germany** states that all persons shall be equal before the law and that no person shall be disfavoured because of disability.
- Section 38 of the **Fiji Constitution (Amendment Act) 1997** stipulates that “a person must not be unfairly discriminated against, directly or indirectly, on the ground of his or her actual or supposed characteristics or circumstances including... disability”.
- The 1995 **Constitution of Uganda** was drawn up with the participation of many different groups in the community, including people with disabilities. That participation is reflected in a number of constitutional provisions guaranteeing and promoting equality for people with disabilities. Article 21 stipulates that a person “shall not be discriminated against on the ground of sex, race, colour, ethnic origin, tribe, birth, creed or religion, or social or economic standing, political opinion or disability.” Article 32(1) stipulates that the state “shall take affirmative action in favour of groups marginalised on the basis of gender, age, disability or any other reason created by history, tradition or custom, for the purpose of redressing imbalances which exist against them”.
- Article 9 of the **Constitution of South Africa** states that “... to promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken”.

## **Approaches to incorporating the CRPD into national law<sup>22</sup>**

- Recognise the civil, cultural, economic, political and social rights of women, men and children with disabilities in the supreme law of your country (constitution or basic law). See the examples in the box on page 39.
- Revise existing provisions in the constitution or basic law and the protection granted to people with disabilities.
- Include a general guarantee of equality.
- Prohibit the use of disability as a ground for discrimination.
- Include specific provisions on the rights of people with disabilities.
- Revise language used to refer to people with disabilities.
- Adopt a national law incorporating the content of the Convention, or even its entire text, specifying that the law is enforceable before the courts.
- Adopt additional implementing legislation. Depending on existing legislation, your country might adopt or amend:
  - a comprehensive, general discrimination law, including the prohibition of using disability as a ground for discrimination in public and private life
  - non-discrimination laws in different sectors, such as work, education and access to justice, including disability as a prohibited ground of discrimination, and/or
  - disability-equality law, prohibiting discrimination based on disability and establishing a broad framework to address disability. The intention is that the disability equality law would create a framework to address disability rights.
- Ensure that there is a mechanism for consulting with people with disabilities, and/or their representative organisations, at the law-making level.
- Revise language used to refer to people with disabilities in all existing and new legislation.

### 3 Introduce coordination across government

*“In my country what I think we need now to improve the situation is to set up a national policy for disabled people; not a different one from the other people but a national policy that recognises the rights of the disabled. As an individual, what I can do is stop the wrong that is going on in front of my eyes (ie, the mistreatment of disabled people, etc). Raise awareness, even if it is for one person.”*

(Girl, 19, Somalia, quoted on UNICEF’s ‘Voices of Youth’ website)

Disability issues within government are often delegated to a ministry of social welfare or equivalent and then ignored by all other government departments. This means that children with disabilities are not included in mainstream policies and programmes. The Committee on the Rights of the Child has argued, in relation to children, that there is a need for better coordination across

government departments, and between national and local levels of government. The aim of coordination is to ensure that all departments at all levels are informed about the rights of children, and work consistently to promote them. There is a similar need for coordination in respect of disability.

Article 33 of the CRPD requires the designation of one or more focal points within the government with responsibility for the implementation of the Convention. These focal points, for example, can have a responsibility for taking a lead role on disability issues across government, informing departments about their responsibilities under the Convention, and scrutinising proposed legislation and policy for compliance with its principles and standards.

Governments are also required to consider the establishment of a coordinating mechanism across government. The aim would be to ensure that all government departments, at every level, understand the implications of

### Action taken by the South African government<sup>23</sup>

South Africa has established the Office on the Status of Disabled Persons, responsible for implementation of the Integrated National Disability Strategy. It is sited in the President’s Office, giving it a high profile and status, and sending out a powerful message to the wider society of the significance the government attaches to the issue.

This pan-governmental approach is embedded in the government’s strategy to promote the rights of disabled people, and has been cascaded to the provinces. Each government department is required to establish a disability unit and to

undertake a disability audit to identify action needed to ensure implementation of the strategy, as well as reserving 10% of its budget for disability issues.

The departments to which recommendations are addressed in the strategy include health, education, welfare, labour, justice, arts, culture, science and technology, foreign affairs, welfare and population development, public works and transport. The recommendations spell out not only the action required by the relevant government department, but also the other bodies with which it should collaborate.

the Convention for their own areas of responsibility, and that there is coherent, coordinated and cross-departmental strategy for implementation.

Clearly, it is not possible to prescribe any one approach to coordination for all governments. There are many different ways in which it can be achieved effectively. One example is through the development of a specific department or unit with direct access to the prime minister or president. This gives visibility and authority to disability, and facilitates oversight of policy across all government departments. In some countries, this model has been strengthened by the development of national strategies on disability with the unit taking a lead on promoting their implementation. In respect of children with disabilities, it would be necessary to establish effective collaboration between any such approaches and comparable mechanisms set up to promote implementation of the UNCRC. Without collaboration between the two, there is a danger that children with disabilities will be ignored in both.

#### **4 Ensure that both public and private sectors respect the rights of children with disabilities**

The lives of children with disabilities are affected by the actions of governments and public bodies. But much of what happens to them is also influenced by individuals and private organisations or companies. The CRPD includes a number of measures which make it clear that governments must take action to ensure that the rights of children with disabilities are respected by all sectors. They must:

##### **Take into account the protection and promotion of the rights of people with disabilities in all policies and programmes – Article 4(c)**

Nearly all government policies and programmes will have some impact, either directly or

indirectly, on children with disabilities. They are obviously affected by policies on education, health, childcare, play and youth services. However, broader issues such as social protection, transport, macroeconomic policy, planning, environment, housing and water and sanitation are also relevant for their lives. When such policies are being developed, governments need to consider their potential implications for people with disabilities, including children.

The Millennium Development Goals (MDGs), which range from halving extreme poverty to halting the spread of HIV and AIDS and providing universal primary education by 2015, were targets agreed by all the world's countries at the beginning of the 21st century. They cannot be achieved without greater investment in the realisation of the rights of people with disabilities, who are usually among the poorest in all societies, with the least access to education and healthcare. Accordingly, in 2008 the UN Commission for Social Development adopted a resolution entitled "Mainstreaming Disability in the Development Agenda".<sup>24</sup> Governments, too, need to reflect this commitment to mainstreaming in their policies at national level, including, for example, in Poverty Reduction Strategy Papers, and strategies aimed at education for all.

##### **Refrain from actions inconsistent with the CRPD – Article 4(d)**

Governments must not do anything that is inconsistent with the Convention, such as the introduction of legislation allowing forced sterilisation of children with disabilities, or making disparaging or negative comments on disability. However, they are also required to take action to make sure that all public bodies behave in ways that comply with the rights in the Convention. This means that all policies and guidance to public bodies must take account of the Convention. There will need to be some form of regulatory body to monitor their actions, and to intervene when they fail to act appropriately.

## The Millennium Development Goals (MDGs)

The MDGs need to be considered in respect of children with disabilities, who are disproportionately disadvantaged in realisation of the Goals to date.

### **GOAL 1 Eradicate extreme poverty and hunger**

- Poverty as a cause of disability: well over 50% of disabilities are preventable and directly linked to poverty. This is particularly true for disabilities arising from malnutrition, maternal under-nourishment and infectious diseases.
- Disability as a risk factor for poverty: over 85% of people with disabilities live in poverty.

### **GOAL 2 Achieve universal primary education**

- An estimated 90% of children with disabilities in the developing world do not attend school.

### **GOAL 3 Promote gender equality and empower women**

- It is widely recognised that women and girls with disabilities are doubly disadvantaged in society: they are excluded from various activities because of both their gender and their disability.
- Women and girls with disabilities are twice to three times more likely to be victims of physical and sexual abuse than women without disabilities.

### **GOAL 4 Reduce child mortality**

- Mortality rates for children with disabilities can be as high as 80% in some countries, even in those countries where mortality rates among children who have no disabilities is below 20%.

### **GOAL 5 Improve maternal health**

- Approximately 20 million women and girls become disabled each year as a result of complications during pregnancy or childbirth.
- Abnormal prenatal events are a major cause of disability in children in the developing world. Such disabilities can often be prevented.

### **GOAL 6 Combat HIV and AIDS, malaria and other diseases**

- People with disabilities are particularly vulnerable to HIV and AIDS but typically lack the necessary services and access to information on prevention and treatment.
- One in ten children with disabilities has a neurological impairment, including learning disabilities and loss of coordination and epilepsy, as a consequence of malaria.

### **GOAL 7 Ensure environmental sustainability**

- Poor environmental quality is a significant cause of ill health and disability.
- Trachoma is the main cause of preventable blindness, and can be prevented with access to safe water.

### **Legislate to eliminate discrimination by private bodies – Article 4(e)**

Governments must take action to eliminate discrimination by private bodies and individuals. This may be done through a variety of means including legislation, codes of practice, inspection and monitoring. For example, many care facilities are privately run. They must have the same obligations as state-run bodies, to respect the rights of children with disabilities and not to discriminate against them in any way. The same obligations will apply, for example, to shops, restaurants, organisers of cultural or sports activities, religious bodies, private schools, employers and other commercial organisations.

### **Collect and disaggregate statistics and data – Article 33**

Article 31 of the CRPD requires governments to collect information to enable them to develop and implement policies to ensure the realisation of the rights of children with disabilities. The statistics and research data must be disaggregated, for example, by gender, age, and ethnicity. They must also be used to identify and address the barriers faced by children with disabilities in exercising their rights. In other words, the focus should not be on collecting data on specific impairments, but rather on the number of people who experience barriers, for

example, in using public transport, the number of people who need access to sign language, or whether children with disabilities are included in the Education Management Information System (EMIS).

One of the difficulties in many countries in providing appropriate services for children with disabilities is the lack of information about the prevalence of disability and its impact on the realisation of rights. The problem is compounded by the lack of birth registration of children with disabilities. Overall, up to 50 million births are unregistered each year, an estimated 30% of all births, and children with disabilities are disproportionately represented among them. Universal registration is essential for providing governments with accurate data with which to assess the numbers of children with disabilities who are being denied, for example, the right to education, and to plan for the fulfilment of children's educational, as well as other rights. Lack of parental documentation, inability to pay any fees, reluctance to pay for a child with a disability, lack of access to the registration systems, parental illiteracy and lack of understanding of the significance of holding a birth certificate, all contribute to the failure to register children's births.

Article 18 of the CPRD reaffirms the provision in the UNCRC that every child has a right to

## **Discrimination against children with disabilities in the statistics<sup>25</sup>**

In Vietnam, when the school attendance rates are calculated, children with disabilities, along with unregistered and migrant children, are first subtracted from the total of children of primary school age. In other words, there is a

presumption that children with disabilities will not attend school and that they therefore do not need to be included in the calculation of how successful schools have been in getting children into education.

## Global strategies to improve data collection<sup>26</sup>

To support the collection of accurate data on children with disabilities, the World Bank and the Organisation for Economic Co-operation and Development (OECD) have agreed and signed a Memorandum of Understanding on Childhood Disability Screening in Developing Countries. The aim is to accelerate the

achievement of Millennium Development Goal 2 – to achieve universal primary education. This joint effort aims to support the gathering of qualitative data on disabled children aged 2–9 by introducing a methodology that can be used in all developing countries.

be registered at birth. States need to introduce a universal requirement to register every birth. They can support this obligation, for example, by ending the legal requirement that parents present their own identity papers. In addition to legislation, strategies to increase rates of birth registration include mobilisation campaigns to increase public demand, elimination or reduction of registration fees, and simplification of registration procedures.

Finally, it is important that data is never used to breach the privacy or confidentiality of people with disabilities. There must be safeguards, therefore, including legislation on data protection, to protect privacy and ensure that data collection and usage complies with internationally accepted principles to protect human rights.

### **5 Involve children with disabilities in the development, implementation and monitoring of laws, policies and decision-making processes**

Article 4(3) stresses that when developing legislation and policies to implement the CRPD, as well as in all other relevant decision-making

processes, governments must consult and actively involve people with disabilities, including children, through their representative organisations. It is important to recognise that it is not sufficient to rely on adults with disabilities to represent the experience and perspective of children. Experience since the adoption of the UNCRC has demonstrated the importance of consulting directly with children in order to ensure the best possible decisions, policies and legislation. They can be consulted, for example, through their own child-led initiatives, where they exist, through children's advisory committees of organisations of people with disabilities or other NGOs working with children, through schools or other youth organisations, through parents' groups, and through the Internet or national surveys.<sup>27</sup>

Article 33(3) of the CRPD requires that governments recognise the key role that civil society organisations and, in particular, people with disabilities and their representative organisations must play in the process of monitoring implementation of the Convention. People with disabilities will need to be directly involved in the design and establishment of any monitoring mechanism, as well as active within it.

## Statement from children with and without disabilities

Children participating in a consultative workshop in Sanaa, Yemen (29–31 October 2007) made the following statement.

### **We call on the government to take the following action to realise the rights of children with disabilities:**

- Bring an end to psychological abuse.
- Allow all children access to inclusive education.
- Provide accessible streets, transport, public parks, leisure centres and play areas.
- Promote positive attitudes towards disability.
- Encourage the media to run extensive awareness campaigns for non-disabled children on how to deal with children with disabilities.
- Adapt all buildings and schools for use by children with disabilities.
- Train all teachers to work with children with disabilities in inclusive environments.
- Promote the active participation of children with disabilities in their communities.
- Train children with disabilities in self-defence arts.
- Cooperate with NGOs to address the issues of disability.

### **We call on civil society organisations to:**

- Support regular demonstrations and sit-ins to enhance the role of children with disabilities, and support their rights in education, medical care and participation in the community.
- Spread understanding of the Convention on the Rights of Persons with Disabilities.

## 6 Establish independent human rights institutions

Article 33(2) requires governments to establish independent bodies for promoting, protecting and monitoring the CRPD, for example, in the form of national human rights institutions. There are agreed international principles, known as the 'Paris Principles', which outline how these bodies should be established and the powers they require to function effectively. The CRPD explicitly requires that these principles

are taken into account (see below). Such institutions need to have a special focus on children with disabilities. This can be achieved by ensuring specific focal points on disability and on children within generic human rights institutions, which can collaborate on issues of relevance to children with disabilities. Alternatively, where children's ombudspersons or children's rights commissioners exist, it is important to ensure that they give specific attention to children with disabilities and are fully accessible and responsive to them.<sup>28</sup>

## South Africa's approach<sup>29</sup>

The South African Human Rights Commission (SAHRC) has both a disability and a children's commissioner. It undertook a wide-ranging consultation in 2000 with both disabled and non-disabled children to ascertain their

priorities for the Commission's work. The SAHRC also has advisory committees comprising representatives of various stakeholders and experts to advise it on policy issues relating to disability and children.

### The Paris Principles<sup>30</sup>

The Paris Principles suggest that institutions should have the following characteristics:

- the competence to promote and protect human rights
- as broad a mandate as possible, set forth in a constitutional or legislative text, specifying the institution's composition and sphere of competence
- responsibilities to provide to parliament, government and other competent bodies opinions, recommendations, proposals and reports on any matters concerning the promotion and protection of human rights – either on request or through the office's power to consider matters without any higher referral
- the right to publish opinions and reports independently, including commenting on the current state of the law and developments affecting human rights and any violations
- general duties and necessary powers to enable the institution to promote and ensure harmonisation of national legislation, regulations and practice with the international human rights instruments to which the State is a party, and their effective implementation; encourage ratification or accession to these instruments
- the right to comment on the reports which States are required to submit to UN bodies and committees and to regional institutions, and where necessary to express an opinion on the subject, "with due respect for their independence"
- to cooperate with UN and UN-related organisations and regional and national human rights institutions
- to help formulate programmes for teaching and researching human rights and take part in them in schools and universities and among professionals
- to publicise human rights and efforts to combat discrimination, by increasing public awareness – particularly through information and education and use of the media.

## 7 Make sure the CRPD is known

### Dissemination of information

Article 42 of the UNCRC requires governments to ensure that its provisions are known both to adults and children. Children cannot exercise their rights unless they know they have them. Although the CRPD does not include a directly comparable provision, Article 8 does require that efforts are made to encourage the media to raise awareness and foster respect for the rights of people with disabilities. The Committee on the Rights of the Child has argued that governments should develop strategies for disseminating knowledge of the UNCRC throughout society.

It is clearly necessary to develop comprehensive strategies to promote

awareness of the rights the CRPD contains and how to exercise them. The text of the CRPD needs to be available in all languages of the country, as well as in a variety of accessible formats including Braille, large print, audio, plain or child-friendly language, and electronic modes of communication. Measures must be taken to make the CRPD widely known and understood, both by people with disabilities, including children, and by the wider society – including families, professionals, policy-makers, members of parliament, human rights organisations, civil society and religious organisations. In addition, children with disabilities also need information on where they can go for help in realising their rights and who has responsibility for implementing them.

### **Rights cannot be exercised if you do not know you have them!<sup>31</sup>**

A five-year-old child, living in a rural area in El Salvador, had a brain tumour. His mother needed to take him to hospital for an X-ray to see if it had grown. The overall cost of doing so was approximately \$200 because of the bus fares and the need for overnight accommodation. A local community-based rehabilitation scheme had raised \$120 for the family, but the remainder of the costs were still outstanding. Both parents were without work and had no means of finding the money. The Ministry of Health responded to this story by arguing that the child was entitled to help with the costs. A means-tested system prevailed and poor families could get free healthcare, transport and accommodation. However, neither the family nor the local health centre were aware that such help was available.

## OHCHR raises awareness in the Maldives<sup>32</sup>

The UN's Office of the High Commissioner for Human Rights (OHCHR) undertook an awareness-raising mission to the Maldives to promote understanding of the Convention on the Rights of Persons with Disabilities and its Optional Protocol. Meetings were held with various government departments with responsibility for human rights and disability, members of parliament, the National Human Rights Commission, the Resident Co-ordinator and representatives of UN specialised agencies and other members of the UN country team. A meeting for national and international NGOs attracted over 100 participants, and another

meeting brought together some 50 parents and children with disabilities.

The mission revealed a deep interest in learning more about the Convention and identified areas where further knowledge was necessary, such as on the right to education, national implementation institutions and the need for dedicated staff to work on the Convention to ensure successful implementation. At the end of the mission, the government announced its intention to recommend to the President that the Maldives ratify the Convention.

### Human rights education

Article 29 of the UNCRC specifies that one of the aims of education is to develop respect for human rights and fundamental freedoms. Article 24(1)(a) of the CRPD also affirms that strengthening respect for human rights is a key aim of education. In its General Comment on the Aims of Education, the Committee on the Rights of the Child emphasises that human rights education needs to include information on the content of human rights conventions, and that children should also learn about human rights by seeing the principles implemented in practice.<sup>33</sup> School curricula need to be designed to include information about the CRPD alongside other human rights conventions. It also means that measures must be put in place to promote environments in schools where children learn to respect each other's rights and to challenge discrimination between members of the school community, including on grounds of disability.

### Training

One of the general obligations included in Article 4 of the CRPD is a requirement to promote training for professionals and staff working with people with disabilities. Professionals play a significant role in the lives of children with disabilities – such as teachers, doctors, nurses, social workers, childcare staff, nursery nurses, police and residential care staff. It is vital that they are fully informed about the rights in both the UNCRC and the CRPD. The Committee on the Rights of the Child has recommended that training on the rights of children (and this will include children with disabilities) should be “practical, systematic, and integrated into professional training to maximise its impact and sustainability. It should equip professionals with skills and attitudes that enable them to interact with children and young people in a manner that respects their rights, dignity and self-respect”.<sup>34</sup>

## 8 Undertake research

Article 4(g) and (h) introduces an obligation on governments to undertake or promote research and development of universally designed goods, services, equipment and facilities that need the least possible adaptation and cost to people with disabilities. They also require research to be promoted into universal design and new technologies for people with disabilities. People with disabilities must be provided with accessible information about mobility aids, devices and assistive technologies as well as other forms of assistance, support services and facilities.

## 9 Promote international cooperation

Implementation of the CRPD is a cooperative process for the governments of the world. Article 32 of the CRPD emphasises that international cooperation is vital if the provisions of the Convention are to be realised for all people with disabilities. When States ratify the Convention, they are not only committing themselves to implementation in their own country but also, where appropriate, to provision of support and cooperation with other states. In particular, Article 32 proposes that governments introduce measures that include:

- international cooperation, including international development programmes that are inclusive of and accessible to people with disabilities. It is important that children with disabilities are also explicitly acknowledged in these programmes

- facilitating and supporting capacity-building through the exchange and sharing of information, experiences, training programmes and best practices
- facilitating cooperation in research and access to scientific and technical knowledge
- providing technical and economic assistance, including by facilitating access to and sharing of accessible assistive technologies and through the transfer of technologies.

However, the commitment to international cooperation does not undermine the responsibility of individual States to fulfil their obligations within their own country.

## 10 Report to the UN Committee on the Rights of Persons with Disabilities

In addition to obligations to implement the provisions and introduce mechanisms for monitoring the CRPD at national level, governments are also required to participate in a process of international monitoring. Articles 34–37 of the CRPD establish the process for international monitoring, as follows.

### Establishing the Committee

The Committee had to be established within six months of the CRPD coming into force.<sup>35</sup> Initially, it will have 12 members but this will increase to 18 once 80 countries have ratified. Governments that have ratified (ie, States Parties) can nominate candidates for the Committee, and when doing so must consult with people with disabilities, including children,

through their representative organisations. When electing members of the Committee, consideration must be given to geographical balance, representation of different political and legal systems, balanced gender representation and the participation of people with disabilities.

### **Committee members**

Members serve in their personal capacity and must have recognised competence and experience in the field of disability rights. They are elected for a period of four years and are eligible for re-election once. They are empowered to establish their own rules of procedure and will elect their own Chair and other officials.

### **Reporting to the Committee**

The primary function of the Committee is to consider reports submitted by governments on measures taken to fulfil their obligations under the Convention, as well as any difficulties they are experiencing that impede implementation. These reports must be submitted initially two years after ratification, and subsequently every four years. The Committee will develop guidelines for governments on how they should prepare their reports. However, the Convention specifies that governments shall be encouraged to create an open and transparent process that allows for participation of civil society. In particular, they must consult with people with disabilities, including children, through their representative organisations.

### **Consideration of reports by the Committee**

The Committee will consider the reports and will then issue what are known as 'Concluding Observations', which are sent to governments. They include suggestions and recommendations as to actions a government could take to fulfil its obligations, under the Convention, more effectively. Governments are expected to make these Concluding Observations widely available to the public in their own countries, and to encourage widespread access to their suggestions and recommendations. The Committee can also send the reports to UN agencies or programmes in order to request technical advice or assistance in the implementation of any of their recommendations. The Concluding Observations are a very important tool for lobbying domestically, particularly for disabled people's organisations and NGOs.

### **Co-operation between governments and the Committee**

Governments must co-operate with the Committee and assist its members in their role in reviewing progress on implementation of the Convention. On its part, the Committee is expected to give consideration to all possible ways of strengthening national capacities to implement the Convention, including through international cooperation.

The Committee may also undertake inquiries where it has cause for concern that there are serious violations of rights under the CRPD (see page 31).

## Checklist on implementation

Has your government:

- ratified the Convention and introduced any necessary enabling legislation to bring it into force?
- reviewed the supreme law of the land (constitution or basic law) to ensure that it protects and recognises the civil, cultural, economic, political and social rights of people with disabilities?
- undertaken a review of existing legislation to ensure compliance with the CRPD?
- introduced non-discrimination legislation?
- ensured that sufficient budget allocations are available to enable the implementation of the CRPD?
- collected disaggregated information on the lives of children with disabilities?
- consulted with children with disabilities in all law and policy reviews?
- made information on the CRPD available in accessible formats?
- introduced free birth registration and launched a campaign to raise awareness of the right to and necessity for birth registration?
- introduced human rights education into the school curriculum?
- provided training on the CRPD for all professionals working with children with disabilities?
- established disability focal points within government?
- introduced a coordinating mechanism across government to ensure integration of children with disabilities into mainstream policies and services?
- established a human rights institution or children's ombudsman or children's rights commission?
- introduced mechanisms for redress when rights are violated?
- provided children with disabilities with information about aids, assistance and services available?
- undertaken research into universal design and new technologies?

## The responsibilities of other actors

Although governments have the primary responsibility for the realisation of the rights of children with disabilities, these rights will not be realised without the active support and engagement of many other actors – for example, parents, teachers, religious communities, civil society organisations, business people, local politicians and policy-makers. Human rights go beyond being legal entitlements that can be realised through the enactment of legislation and policies. They are also principles that need to inform the day-to-day relationships between individuals and their communities. All members of society need to fulfil their responsibilities in their own practice, attitudes and language, to promote the creation of inclusive environments in which the rights of all children, including those with disabilities, are respected and valued.

The other main actors with responsibility for ensuring that the rights of children with disabilities are respected are:

- parents and other caregivers
- local authorities
- schools
- civil society organisations and the private sector
- the international community.

### Parents and other caregivers

Parents or other caregivers have key responsibilities for ensuring the realisation of the rights of children with disabilities. They have the most direct impact on their day-to-day lives, and children with disabilities argue consistently that changes in their parents' attitudes and understanding would be the most effective

means of ending their social exclusion. Of course, parents cannot protect their children's rights fully without the government also fulfilling its responsibilities.

The responsibilities of parents include:

- registering the birth of a child with a disability
- providing equality of care between all children in the family, including children with disabilities
- respecting the capacities of a child with a disability to take a growing level of responsibility for decisions affecting them
- ensuring that where a school place is available, the child is enabled and encouraged to go
- providing support to children with disabilities in their education, for example, by learning sign language to facilitate communication, attending school meetings, helping with homework
- where a school place is not available, advocating for the child's right to education – holding schools and education authorities to account in fulfilling their obligations to children with disabilities
- ensuring that children with disabilities are provided with the same quality of access to food, water and shelter as other children in the family
- ensuring that, to the maximum extent possible, children with disabilities are able to access the healthcare they require
- challenging prejudice and discrimination within the local community
- inclusion of children with disabilities in all social and cultural events on an equal basis with all other children
- facilitating opportunities for children with disabilities to play and associate with other children.

## Local authorities

Children are not islands. They live not only in families, but also in communities, whose values, culture and level of engagement have a significant impact on their day-to-day lives. Therefore, local authorities working at community level have a key role to play in creating environments that are conducive to ensuring that the rights of children with disabilities are realised.

### Promoting local awareness

Local authorities, including traditional leaders, in collaboration with partners within the community, have responsibilities to promote awareness of the rights of children with disabilities among local communities. Work needs to be undertaken with parents and the wider family, as well as religious and other community groups, to help challenge discrimination, ignorance and myths surrounding disability.

### Addressing the barriers

In any locality it will be necessary for local authorities and, where appropriate, traditional leaders, in partnership with community members, to undertake an analysis of where the barriers to the rights of children with disabilities lie. Action can then be taken to address the specific barriers that arise. This might include:

- raising awareness of the CRPD and the equal rights of children with disabilities
- sensitisation as to the nature of disability and the capacity of children with disabilities to benefit from education
- promoting and supporting inclusive learning environments, including early years settings, and schools at all levels
- promoting campaigns to encourage the birth registration of all children, including children with disabilities
- providing information about any social security benefits and support services available

- collaborating with the disability community, including children, to identify the physical barriers to inclusion and taking action to remove them – for example, providing ramps, accessible toilets, road crossings
- providing information to schools, hospitals and clinics on how to create more accessible environments
- listening to children and engaging them as active participants in challenging discrimination and social exclusion
- developing inclusive play facilities.

### Providing accurate information on children with disabilities

Information at local level is needed in order to ensure that the numbers of children with disabilities are known. Only with this information is it possible to ensure that the range of services provided is consistent with the needs within the community. The process of mapping can be undertaken in partnership with local disabled people's organisations, traditional leaders, local community members, religious organisations or parent groups. Birth registration is an important factor in building up accurate records of child populations and school can play a key role in providing a locus for birth registration.

## Schools

Governments have the responsibility for ensuring that the educational infrastructure is in place to ensure the right of all children with disabilities to attend school. However, teachers also have clear duties to translate legislation and policies, designed by governments, into meaningful practice at school level, and ensure that they create a culture which is inclusive and respectful of every child. (For details of action to be taken by schools, see pages 106–117.)

## Civil society organisations

In most countries throughout the world, international, national and local civil society organisations play a central role in the realisation of rights, whether as service providers or as advocates challenging other key actors to fulfil their obligations. They are often the source of considerable expertise, not only on where gaps in provision exist within local communities, but also on the strategies needed to address those gaps. The private sector is also playing an increasingly important role in the provision of basic services, and needs to comply with its corresponding legal and other obligations.

Disabled people's organisations have been at the forefront of challenging discrimination and promoting social inclusion of people with disabilities. Other NGOs have played a key role in promoting the rights of all children, including those with disabilities. Such organisations can be seen to play a role on either the demand or the supply side:

- On the **demand side**, they have a role to play in undertaking advocacy and lobbying, and also ensuring accountability and transparency of government and other actors by, for example, monitoring whether government policies and programmes have been effectively implemented.
- On the **supply side**, they can undertake capacity-building with communities, parents and traditional leaders, through training, awareness-raising and sensitisation. They can support opportunities for communities to participate in, for instance, social auditing and monitoring of government services. They can also provide training and sensitisation of government officials to improve the quality of legislation and policy and their effective implementation.

## The international community

The international community has a key role to play in providing support to build the capacity of both governments and individuals in the realisation of the rights of children with disabilities. Development partners can utilise a range of strategies to promote the rights of these children, including:

- **Mainstreaming the inclusion of children with disabilities** into all education and other relevant programmes they support.
- **Providing technical expertise and building capacity** to help States meet their commitments to children with disabilities.
- **Enhancing the capacity of children with disabilities and their advocates to claim their rights.** This will involve training and support on human rights to enhance the capacity of people with disabilities, including children, to advocate for and claim their rights, and the creation of opportunities for them to do so, as well as support to others to advocate on their behalf
- **Holding States to account.** Partners with a commitment to the human rights of children have obligations to hold States to account on the commitments they have made in ratifying international human rights treaties.
- **Supporting the collection and analysis of data** from a national, regional and international perspective to facilitate informed policy-making. This will also allow for cross-country comparisons of progress, and will help identify promising programmes or practices, as well as analysing the conditions under which those best practices can be adopted by countries facing similar challenges.

# 6 Advocacy to promote implementation

This chapter explores the action that needs to be taken by disability and child rights advocates to raise awareness of the rights of children with disabilities and promote the recognition and realisation of their rights. It is not an exhaustive list of activities. Rather, it sets out to stimulate ideas and strategies. How you prioritise activities will depend on the political, social, economic and cultural context in which you are working.

## Find out about the lives of children with disabilities

It is not possible to begin to address the rights of children with disabilities unless you have a clear understanding of what rights are being violated, why they are being violated and where. Once you have done the analysis you will have the information to:

- highlight the most important issues
- identify what needs to change and how
- create messages to communicate the need for change.

## Situation analyses

You need to undertake an analysis of the situation of children with disabilities. This should be as comprehensive as possible and it may help to have different organisations leading on different policy areas – for example, health, education, poverty or social inclusion – or on

different types of disability. A situation analysis needs to cover the following:

- **Analysis of the legislative, policy and practice environment** – is the necessary legislation in place to eliminate discrimination and promote equality of opportunity? If legislation exists, is it implemented? If not, is this because of inadequate resources, lack of policies, lack of public demand, or inadequate information, awareness and training? What legislative and policy changes are needed? Are there mechanisms for seeking redress when rights are violated? Are they accessible to children with disabilities?
- **Analysis of the responsibilities of different actors** – who are the various groups or people responsible for realising the rights of children with disabilities? For example, in education it is governments that bear the primary responsibility for providing accessible schools and the necessary facilities for children with disabilities, training teachers, and legislating to eliminate discrimination, and for providing and promoting equality of educational opportunity. But other key players also have significant responsibilities – for example, local authorities, schools, parents, local communities and academia, although their capacities to fulfil these responsibilities are dependent on governments meeting their primary obligations.

- **Applying the general principles of the UNCRC and CRPD** – are the general principles of both Conventions understood and complied with by governments in legislation, policy, resource allocation and service delivery?
- **Analysis of rights violations** – what rights are being violated? What are the immediate, underlying and structural causes? For example, if children with disabilities are frequently placed in institutions, it may be that the immediate causes are rejection by families and lack of foster carers. The underlying causes may be health professionals' belief that institutional care is preferable, a lack of understanding of disability, or inadequate training. The structural causes may be poverty, poor housing, inadequate service provision to families and deep-seated prejudice surrounding disability.
- **A participatory approach** – have all the relevant stakeholders been consulted in your situation analysis, including the opportunity to feed back on its conclusions – for example, disability organisations, children with disabilities themselves, as well as parents, teachers, religious leaders and community groups?
- **Data that is disaggregated** – is there available data on the situation of children with disabilities, disaggregated by gender, age and ethnicity? If not, have you identified where the gaps are?

### Assessing capacity for implementation

You need to assess the capacities of children, caregivers and other members of the community to claim their rights and how these capacities can be strengthened, as well as the capacities of those with responsibilities to fulfil their obligations. Also, what barriers to implementation exist – for example, lack

of resources, knowledge, commitment, coordination or authority – and how can these be overcome.

- **Capacities of children with disabilities to claim rights** – do children with disabilities know what their rights are in order that they can claim them? What information do they have about what action the government is taking to fulfil their rights, how decisions are made and by whom, and what mechanisms, if any, exist to seek redress in cases of violations of their rights. What action has been taken to build opportunities for children to claim their rights?
- **Capacities of government and other actors to fulfil their obligations** – do the government, public authorities and other actors have the capacities to fulfil their obligations with regard to the rights of children with disabilities? What and where are the obstacles:
  - lack of resources – either financial, in terms of the tax base or budget priorities, or human, in terms of skills and institutional capacity?
  - lack of authority – legal, moral, spiritual or cultural authority?
  - lack of responsibility – refusing to accept obligations and demonstrating no political commitment to doing so?
  - lack of coordination between levels and sectors?
  - lack of knowledge?

For example, in order to assess parents' capacities to fulfil their obligations to ensure that a child with a disability is provided with an adequate standard of living, it is necessary to analyse the challenges they face, such as the lack of or inadequate state benefits, additional costs associated with the disability, rejection of the child by the wider family and community, abandonment by the father, or lack of childcare to enable the mother to work.

## Where to go for information

In order to build a picture of the lives of children with disabilities, you need to use the widest possible range of sources of information. Where no information exists, you can highlight the gap (and the need to fill it) in your analysis. Possible sources include:

- the constitution
- existing legislation – for example, on discrimination, education, child protection, health, childcare
- government policies
- academic and other research into the lives of children with disabilities
- journal and newspaper articles
- consultations with children with disabilities and their caregivers
- statistical data
- reports by NGOs, human rights institutions or other civil society organisations
- parliamentary reports
- data and research from international sources – eg, United Nations Development Programme (UNDP), UNICEF, World Bank, international NGOs, etc.

## Build capacity

The CRPD is a new treaty and it will be necessary to educate people on what it contains, its implications and how to implement it. It would be useful to develop a cohort of trained advocates with the knowledge and skills to do capacity-building. You might run a series of training workshops to build this cohort, who can then develop a ‘cascade’ approach to training across the country. It is important to involve older children with disabilities, as they themselves can become trainers. Their involvement not only provides them with skills and competencies, but also challenges negative stereotypes about both children and disability.

Capacity-building needs to focus on a number of different audiences:

- **National and local government officials, parliamentarians, etc** – these people have responsibilities and need to know what those responsibilities are and how to fulfil them. You can organise seminars, individual meetings and conferences and provide briefing notes.
- **Children with disabilities and disability and children’s organisations** – if children with disabilities are to be enabled to claim their rights, they, and organisations working on their behalf, need information about what those rights are and how to advocate for change. Training might be provided through networks of NGOs, if these exist.

- **Media** – it is important that the media is aware of the CRPD, both in terms of reflecting its principles in the way it portrays issues of disability and in order to hold the government to account on its obligations to children with disabilities. You might try to meet with key editors and journalists, offer to run briefing seminars or write articles on the CRPD and the rights of children with disabilities, become part of a community radio network, or attend internal meetings to provide information and guidance.
- **Professionals working with children** – understanding of the rights of children, including children with disabilities needs to be embedded in the curricula of all professionals working with or for children. It is important to engage with the educational institutions providing training for teachers, health professionals, social workers, judges, magistrates, police, early years workers, etc, on how to apply the rights in both the UNCRC and the CRPD in their day-to-day practice as well as in the way their services are run. You could also develop simple tools and materials for them to use and adapt.
- **Caregivers and community members** – children's lives are most affected by the people around them who provide care and protection. Community-based training on the rights of children with disabilities will be vital if discrimination, prejudice and social exclusion are to be tackled. You could produce leaflets with simple and accessible messages.

## Radio programme in Nepal<sup>36</sup>

In Nepal, one NGO has sought to fill the gap left by government by broadcasting a weekly programme on public service radio, which gives up-to-date news on the situation of disabled people and their rights. Children with disabilities are also invited to express their views on air. It is estimated that the programme reaches up to 3 million people who would otherwise have no information about disability. It is backed up by the distribution of 4,000 copies of a monthly magazine giving information about the lives of disabled people and how they have overcome barriers to achieve their goals. The value and impact of the initiative is evidenced by the fact that 68 listener clubs have been started all over the country to follow up the issues raised in the programmes. It is estimated that well over 50% of households in Nepal have access to radio, so it is a highly accessible medium of information for the majority of the population.

## Build networks and alliances

You need to build strong alliances in order to be effective in advocating for implementation of the rights of children with disabilities. The more people involved, and the more consistent their demands, the more likely it is that governments will respond. It also means you have access to a wide range of skills, expertise and opportunities for advocacy. Possible partners might include:

- **Parliamentarians** – some countries have all-party parliamentary groups on children and on disability who take the lead in raising issues, encouraging greater understanding among their colleagues, etc. Action could be taken to stimulate interest in establishing such a group on the rights of children with disabilities as a focal point for advocacy within parliament.
- **Senators or Members of Congress men and women** – as above.

## Government and community collaboration<sup>37</sup>

In El Salvador, a regional collaborative programme was set up between the government and local communities to raise awareness of disability, promote social inclusion and improve access to healthcare. In one project, initiated by a doctor working in a local health clinic, a local committee was formed, consisting of parents of children with disabilities, teachers and community and religious leaders. A government agency provided the members of the committee with basic training, comprising one day each on identification and assessment of disability, exercises for muscular control and flexibility and the development of therapeutic tools for manipulation and exercise. The Committee members then applied these skills in offering help to members of their community. They fundraised to get wheelchairs, hearing aids and other assistive devices needed by local children with disabilities, as well as adults. They also worked with local schools to challenge prejudice against children with disabilities and get places for all the local children with disabilities in those schools. And they undertook mapping exercises to build up an accurate database on all disabled people in the community.

The project was not without problems. When it began, members of the Committee, primarily women at that stage, faced huge hostility from many families. Some parents did not want to talk about their disabled child – they were ashamed and wanted to keep the child largely hidden from view. They resented suggestions that the children could be helped, both through assistive devices and through education. Other hostility arose from men in the community, resenting women organising together. Many committee members dropped out, unable to face the aggression and abuse they faced.

However, a core group persevered and the Committee is now widely accepted and valued. At a meeting of the Committee to present their work, a number of women expressed their immense gratitude to the project for the support it had provided. Some spoke of how the exercises they had been taught provided the first pain relief they had experienced in years. One woman talked of how her child had finally been placed in the local school and it had transformed her life – once written off as ‘incapable and defective’, the girl is now learning to read and write, making friends for the first time in her life and acquiring social skills.

- **The disability community** – some countries will have a network or coalition of disability organisations. If one does not exist, it would be important to try to develop one, involving representation from all types of disability. This network can be a focus for coalition-building across the country.
- **Children’s NGOs and community organisations** – many of these organisations may be familiar with the UNCRC but know little about disability. You need to try to engage their commitment and involvement.
- **Academic and research institutions** – academics are useful allies and can contribute to your evidence base regarding the extent and nature of rights violations and the policy implications. You might identify key institutions that have the potential and interest to pursue relevant research agendas on and with children with disabilities.
- **Media** – identify interested journalists and editors in the print media, as well as TV and radio, including community radio, who can promote the messages you are pursuing, and inform the wider public and build awareness. You need to focus on both children and adult media, local and national outlets as well as the professional press.
- **Professional associations and trade unions** – building allies among these bodies can be useful as they will often have access to the government and/or have experience of advocacy. They also often have large memberships and therefore the potential to reach a wide audience.
- **National human rights institutions** – disability tends to be a low priority in many human rights institutions. You need to emphasise their responsibility to engage with the CRPD and, where necessary, provide them with the evidence and impact of the rights violations experienced by children with disabilities.

## Campaign for ratification

It is imperative to persuade the government to ratify the CRPD, if it has not already done so. In order to campaign for ratification you need to do the following:

- Find out the procedure for ratification in your country – for example, is the decision taken by parliament, the president, the prime minister or someone else?
- Identify the person(s) who will be making/influencing the decision – for example, which government department and which officers within it?
- Develop messages that are likely to be persuasive with the government – for example, the need to demonstrate commitment to the human rights of children with disabilities, the need to build on the invaluable contribution made by the government in the drafting process, the potential for international cooperation, the ethical case for protecting the rights of children, or the number of children involved and their potential contribution to national development.
- Identify the most effective messengers within your coalition to press the government on ratification – who will the government be likely to listen to?
- Use your coalition members to write, email and meet with the government, write to the press, lobby the relevant officials, organise meetings, etc.
- Build a wider body of public support to put pressure on the government – you will need to develop simple and accessible arguments as to why they should support the campaign – for example, numbers of children with disabilities, scale of rights violations, how the CRPD can make a difference, level of international support and numbers of signatures, etc.
- Find a champion within the government to spearhead your campaign for ratification.

## Advocate for implementation

As soon as you are familiar with the CRPD, have a clear picture of how the rights of children with disabilities are being both protected and violated, and with a reasonable body of support, you can begin to advocate for change. The strategies you adopt will clearly depend on the local political and social context, but you can consider the following possible activities.

### Raise public awareness

- Develop clear simple messages that can be promoted in the media and wider public to build support and gather momentum.
- Develop a website to promote awareness, provide and exchange information, and

create opportunities for people to join the campaign.

- Produce posters, leaflet and pamphlets that set out the case for change and that can be distributed widely.
- Write articles and try to get them published.
- Produce press releases setting out the problem and what you are asking the government to do, and encourage the media to highlight the issue, raise it with government ministers and, if possible, launch their own campaigns for change.
- Hold conferences and workshops to promote understanding, debate and interest.
- Use the Concluding Observations (see page 66) to highlight where the government is failing to meet its obligations, and to lend legitimacy to your demands for action.

## Save the Children's 'Voice for Education' project in Nepal<sup>38</sup>

Voice for Education is a project initiated by Save the Children in Nepal using role models of children with disabilities who had successfully overcome discrimination, poverty and immense physical and social barriers to become high academic achievers. Initially, the project identified key individuals in villages to mobilise support for encouraging parents to send their children with disabilities to school. Once some

were in school, they began to serve as role models for other families. The project now works by using community motivators to bring forward children as role models to share their stories and advise other communities. These children talk to other children, government officials, parents and the media. The scheme is now operating in 32 villages in three districts.

## Lobby the government

Lobby the government to make the changes you are advocating:

- Provide evidence of the scale and nature of the rights violation you are seeking to address – the more rigorous and accurate your information, the stronger your case will be.
- Be clear about what strategies are needed to achieve the change – legal reform, implementation of existing laws, more resources, better policies, training for staff or increased public awareness.
- Use any relevant existing recommendations to the government from human rights treaty bodies – for example, the Committee on the Rights of the Child may have made recommendations on the rights of children with disabilities in their Concluding Observations.

- Meet with the relevant ministers and government officials to discuss their obligations, the extent to which these are not being complied with, what changes are needed and how they could be achieved and supported. Remember, it is always more effective to provide solutions as well as criticising what is wrong.
- Create opportunities for children with disabilities to meet members of the government to talk about their experiences and what needs to change.
- Offer to provide training to government officials on the CRPD and the rights of children with disabilities.

## Lobby parliamentarians

Lobby parliamentarians to make a commitment to taking measures to address rights violations and promote implementation. There is a range

### Making the case with governments

- The human rights of children with disabilities should be promoted for the same reason that human rights are promoted for all other children – because of the inherent worth and dignity of each human being.
- Children with disabilities in most countries have difficulties in attending school, accessing healthcare, getting opportunities to play and taking part in sports or the arts, and are far more likely to experience physical and sexual violence than other children.
- The only way to ensure that children with disabilities can enjoy their rights is to guarantee them under national law, follow up with action to implement the legislation across all government departments, and make sure that legal institutions enforce respect for those rights.
- It makes no economic sense to deny children with disabilities the chance to become independent and contributing members of society. Dependency is costly for their families and the wider society.
- Everyone is likely to experience disability at some stage in their lives – because of illness, accidents or ageing. It is not about ‘them’ – it is about ‘us’.

of actions you might consider to encourage parliamentary support:

- Produce briefings for them to use in relevant debates.
- Suggest questions that they can raise with the government on how far the rights of the CRPD are being realised and what action is being taken to fulfil its obligations.
- Use election periods to try to get commitments from political parties.
- Identify any potential parliamentary process where the issue can be raised – draft legislation, consultation documents.
- Produce draft sample letters arguing for the

government to take action on a particular issue and ask all your supporters to send them to their local MP.

- Organise a day when all your supporters will lobby parliament on the issue.

### **Empower child advocates**

Children with disabilities can be their own most effective advocates. Action could be taken to train and support children with disabilities to work as peer advocates in school and local communities, as well as through the media and in political processes.

### **Action that parliamentarians could take<sup>39</sup>**

- Raise issues relating to the Convention in parliament.
- Review draft legislation to assess conformity with the Convention.
- Liaise with civil society groups, including organisations representing people with disabilities and human rights organisations.
- Discuss the Convention in meetings and visits to local electorates, local schools, in party meetings, etc.
- Discuss the Convention in speeches to public gatherings, particularly on the International Day for Disabled Persons (3 December).
- Organise meetings with parliamentarians to discuss the Convention.
- Organise television and radio interviews on the Convention.
- Write articles on the Convention for newspapers, journals, magazines and other publications.
- Request that the Convention be translated into national language(s) and widely distributed.
- Request that the Convention be available in accessible formats.
- Ensure that parliament adheres to the Convention with respect to its members and staff with disabilities.
- Advocate for the establishment of a parliamentary committee on human rights and disability, which could have a role in monitoring the Convention, and ensure that other parliamentary committees consider issues related to disability.
- Ensure that every member of parliament has a copy of the Convention and Optional Protocol.
- Ensure that parliamentarians promote the Convention and Optional Protocol in their political work, especially in their constituency.
- Hold parliamentary hearings on the rights of people with disabilities.

## The ‘Defensorias’<sup>40</sup>

The Council for the Human Rights of Adolescents in El Salvador is a group of 150 young people aged between 16 and 22 years who work as ‘defensorias’ of children’s rights. The group comprises both disabled and non-disabled young people and their work involves promoting their rights, monitoring compliance and advocacy on individual cases. They teach both children and adults about the concept of children’s rights and encourage children to exercise those rights. They also advocate in the public policy field to achieve greater compliance with the principles and standards of the UN Convention on the Rights of the Child.

Initially, they had to overcome a deep mistrust among adults who lacked confidence in them because of their youth. They reported how, when they spoke at parents’ committees in schools, the reaction was often one of anger or contempt. However, gradually that is beginning to change. People do now come to them to report cases of abuse and they advise on where to get legal help and what rights exist under the law.

## Monitor implementation

It is important to monitor the action taken by governments to implement the CRPD. You will need to monitor:

- whether the government has introduced the necessary general measures of implementation to create the infrastructure through which the rights of children with disabilities can be realised, including data-gathering, coordination within government, national strategies, supporting or enabling legislation, visibility in budgets, etc
- progress in implementing the specific rights in the CRPD.

You might want to consider the following strategies for monitoring:

## Civil society reporting

Once a government has ratified the CRPD, it will be required to report to the Committee on the Rights of Persons with Disabilities, which has the responsibility for monitoring States progress in implementing the Convention. It is extremely valuable for the Committee to have access to ‘shadow’ or ‘alternative’ reports from civil society organisations in order to provide it with a more critical analysis of the situation than that usually provided by governments. Such a report enables the Committee to gain a sense of the priorities to focus on with governments. Wherever possible, it is important to try to produce one unified report rather than many separate ones from different organisations. An integrated report coming from a coalition or alliance of organisations working with and for children with disabilities will carry more weight with the Committee for a number of reasons:<sup>41</sup>

- It will be more likely to be viewed as providing credible information if many organisations have signed up to it.
- It enables the Committee to gain a sense of the priorities to focus on with governments.
- Committee members receive a huge amount of reading material – an integrated report will be more focused, lack repetition and therefore be more likely to be read and taken seriously.

When producing an NGO report, it is necessary to involve children with disabilities themselves. Their perspectives, experiences and recommendations need to be included.<sup>42</sup>

## **Follow up on Concluding Observations**

After the Committee has met with the government to review its progress in implementing the CRPD, it will produce its Concluding Observations. This is a short document outlining positive developments, issues of concern and recommendations for future action. Coalitions can use these recommendations as a benchmark against which to monitor further progress. For example, you might produce an annual report identifying whether progress has been made in respect of each recommendation. You can also offer to work with the government in elaborating the necessary legal reforms, policy developments and strategies to implement the recommendations.

# 7 Understanding the rights of children with disabilities: analysing the UNCRC and the CRPD

**Note:** The focus of this guide is on children with disabilities, and therefore we have analysed the provisions of the CRPD exclusively in relation to children. Some of these provisions are **only** relevant for children, such as birth registration, child protection, play, primary education, early identification, and abandonment at birth. However, many of the provisions described in this chapter apply as well to adults with disabilities.

This chapter provides an overview of the nature of rights violations experienced by children with disabilities, together with a detailed analysis of the rights embodied in the **UNCRC**, and the relevant provisions of the **CRPD**. It also takes account of the **General Comment** on the Rights of Children with Disabilities developed by the Committee on the Rights of the Child. The chapter provides concrete suggestions as to the actions needed on the part of government and other duty bearers to fulfil, respect and protect the rights of children with disabilities.

It is important to understand how the two Conventions complement and reinforce each other in order to undertake effective advocacy in respect of children with disabilities:

- The UNCRC sets out the **rights which must be respected for all children**,

including children with disabilities. Article 23 of the UNCRC sets out the specific obligations that States must comply with in respect of children with disabilities.

- The CRPD builds on the UNCRC to introduce specific measures needed to protect the rights of people with disabilities including children. It does this in three ways:
  - In some instances, for example, the best interests of the child, the CRPD simply **reaffirms an existing right** and emphasises that it must be respected for children with disabilities on an equal basis with all other children.
  - With regard to some rights contained in the UNCRC, such as protection from violence and education, the CRPD places **specific obligations on governments** to ensure that those rights are realised for children with disabilities.
  - Finally, the CRPD includes some **additional provisions** which are not included in the UNCRC – for example, concerning sport, personal mobility, and habilitation and rehabilitation.None of these measures constitutes new human rights. Rather, they introduce obligations on governments to remove the barriers that currently impede the realisation of the rights of children with disabilities.

- The General Comment on the Rights of Children with Disabilities provides the **interpretation of the UNCRC by the Committee on the Rights of the Child, as it relates to children with disabilities**, and the Committee’s recommendations as to how they should be implemented by governments.<sup>43</sup> It therefore provides more detailed guidance to governments on how to implement the rights of children with disabilities. Other General Comments on aspects of the UNCRC are also relevant to children with disabilities.

## How the CRPD relates to the UNCRC

The following table provides a brief overview of how the CRPD builds on and complements the rights in the UNCRC for children with disabilities. It can be used as a source of reference for the analysis of the UNCRC and CRPD in this chapter.

**Note:** Both the UNCRC and the CRPD contain provisions (in Article 41 and Article 4 respectively) implying that nothing in that Convention will affect any provisions that are more protective of the rights of children with disabilities in national or international law in force in the States Parties.

**Table. Relationship between the UNCRC and the CRPD**

UNCRC	CRPD
<p><b>Definition</b></p> <p><b>Article 1</b> – for the purposes of the UNCRC, a child is defined as every person below the age of 18 years.</p>	<p><b>Article 1</b> – the CRPD applies to all people, including all children, with disabilities, including those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, can prevent their ability to participate equally in society.</p>

*continued opposite*

**Table. Relationship between the UNCRC and the CRPD** *continued*

<b>UNCRC</b>	<b>CRPD</b>
<p><b>Non-discrimination</b> (a general principle of the UNCRC)</p> <p><b>Article 2</b> – the right to non-discrimination on any ground, including disability, and the obligation of States to take all appropriate measures to protect children from all forms of discrimination.</p>	<p><b>Article 2</b> – defines discrimination on the basis of disability as any exclusion or restriction that prevents the realisation of rights on an equal basis with others.</p> <p><b>Article 3</b> – non-discrimination, equality of opportunity and equality between men/boys and women/girls are general principles of the CRPD.</p> <p><b>Article 4</b> – duty on States to eliminate discrimination.</p> <p><b>Article 5</b> – prohibition of discrimination on grounds of disability, and obligation on States to provide reasonable accommodation to promote equality and eliminate discrimination.</p> <p><b>Article 6</b> – obligation to take measures to address the multiple discrimination faced by women and girls with disabilities.</p> <p><b>Article 8</b> – States must adopt wide-ranging measures to raise awareness of the rights of people with disabilities, combat prejudice and discrimination, promote positive images of disability, encourage respect for people with disabilities in the education system and provide awareness training on disability.</p>

*continued overleaf*

**Table. Relationship between the UNCRC and the CRPD** *continued*

UNCRC	CRPD
<p><b>Best interests</b> (a general principle of the UNCRC)</p> <p><b>Article 3</b> – the best interests of the child must be a primary consideration in all actions concerning children taken by public and private bodies. Services, facilities and institutions caring for children must comply with appropriate standards in respect of health, safety, quality of staff and proper supervision.</p>	<p><b>Article 7</b> – reaffirms that the best interests of the child with disabilities must be a primary consideration.</p> <p><b>Article 16</b> – all facilities and programmes for people, including children with disabilities, must be monitored by independent authorities.</p>
<p><b>Implementation</b></p> <p><b>Article 4</b> – obligation on States to take all appropriate legislative, administrative and other measures to implement the UNCRC. With social, economic and cultural rights, measures must be taken to the maximum extent of available resources.</p>	<p><b>Article 4</b> – sets out detailed obligations to take all appropriate measures to implement the CRPD, including:</p> <ul style="list-style-type: none"> <li>• legislation</li> <li>• protection of rights of people, including children, with disabilities in all policies and programmes</li> <li>• avoidance of actions inconsistent with the CRPD</li> <li>• measures to eliminate discrimination</li> <li>• promotion of universal design, research into new technologies and provision of information and services on available aids and devices</li> <li>• training professionals on the CRPD</li> <li>• consulting with people with disabilities, including children, on all legislation and policies to implement the CRPD</li> <li>• with regard to economic, social and cultural rights, implementation to the maximum of available resources.</li> </ul>

*continued opposite*

**Table. Relationship between the UNCRC and the CRPD** *continued*

UNCRC	CRPD
<p><b>Evolving capacities</b></p> <p><b>Article 5</b> – parents, or other caregivers, have rights and responsibilities to provide direction to children to enable them to exercise their rights. Any direction and guidance must be appropriate and take account of the evolving capacities of the child.</p>	<p><b>Article 3</b> – respect for the evolving capacities of children with disabilities is a general principle of the CRPD, and must be considered in the implementation of all other rights.</p>
<p><b>Right to life</b> (a general principle of the UNCRC)</p> <p><b>Article 6</b> – the right to life of every child and the obligation on States to ensure the maximum possible survival and development of the child.</p>	<p><b>Article 10</b> – reaffirms the right to life and the obligation to take all measures to ensure that it is respected on an equal basis for people, including children, with disabilities.</p> <p><b>Article 25</b> – States must not discriminate against people with disabilities by denying them healthcare or food or fluids.</p>
<p><b>Right to a name and nationality</b></p> <p><b>Article 7</b> – every child must be registered after birth, and has the right to a name, to acquire a nationality and to be cared for by his or her parents.</p>	<p><b>Article 18</b> – affirms these rights for children with disabilities.</p>
<p><b>Right to identity</b></p> <p><b>Article 8</b> – the right to preserve identity, name and family relations.</p>	<p><b>Article 3</b> – affirms the right of children with disabilities to preserve their identity.</p>
<p><b>Non-separation from parents</b></p> <p><b>Article 9</b> – children must not be separated from parents against their will unless necessary for their best interests.</p>	<p><b>Article 23</b> – children with disabilities have equal rights to family life, and must not be separated from parents against their will unless necessary for their best interests. In addition, a child must never be separated from parents because the parent or the child has a disability.</p>

*continued overleaf*

**Table. Relationship between the UNCRC and the CRPD** *continued*

<b>UNCRC</b>	<b>CRPD</b>
<p><b>Family reunification</b></p> <p><b>Article 10</b> – States must deal humanely with applications for children to leave or enter a State to be reunified with family members.</p>	<p><b>Article 18</b> – people with disabilities, including families with a child with a disability, have the right to liberty of movement, and to choose their residence and nationality on an equal basis with others.</p>
<p><b>Illicit transfer of children</b></p> <p><b>Article 11</b> – States must take measures to protect children from being transferred or not returned from abroad, including through bilateral and multilateral agreements.</p> <p><b>Article 35</b> – States must adopt national, bilateral and multilateral agreements to prevent the sale and trafficking of children.</p>	
<p><b>Right to express views</b> (a general principle of the UNCRC)</p> <p><b>Article 12</b> – the right of every child capable of forming a view, to express views and have them given due weight in accordance with age and maturity.</p> <p><b>Article 23</b> – right to active participation within the community.</p>	<p><b>Article 3</b> – full and effective participation is a general principle of the CRPD.</p> <p><b>Article 7</b> – affirms the right of children with disabilities to express views and have them given due weight in accordance with age and maturity, on an equal basis with other children. They must be provided with disability and age-appropriate support to realise this right.</p>

*continued opposite*

**Table. Relationship between the UNCRC and the CRPD** *continued*

UNCRC	CRPD
<p><b>Freedom of expression and opinion, and access to information</b></p> <p><b>Article 13</b> – right to freedom of expression, and to receive and impart information and ideas through all forms of media.</p> <p><b>Article 17</b> – the right to access information from a wide range of sources, and the obligation of States to encourage access through international cooperation, production of children’s books, regard by the media for linguistic minorities, and development of guidelines to protect children from harmful media.</p> <p><b>Article 42</b> – States must take active measures to make the Convention widely known to both adults and children.</p>	<p><b>Article 21</b> – affirms the right to freedom of expression and requires that States take all appropriate measures to ensure that people, including children, with disabilities can exercise the right including by providing information in accessible formats, facilitating and promoting the use of, for example, sign language and Braille, and encouraging private entities and the media to make information accessible.</p>
<p><b>Religious, personal and social freedom</b></p> <p><b>Article 14</b> – right to freedom of thought, conscience and religion.</p> <p><b>Article 15</b> – freedom of association and peaceful assembly.</p>	<p><b>Article 29</b> – right of people with disabilities to participation in political and public life. States must promote the opportunity for people with disabilities, including children, to participate in non-governmental organisations, and form and join their own organisations.</p>

*continued overleaf*

**Table. Relationship between the UNCRC and the CRPD** *continued*

UNCRC	CRPD
<p><b>Right to privacy</b></p> <p><b>Article 16</b> – right to protection from arbitrary interference with privacy, family, home or correspondence.</p>	<p><b>Article 22</b> – people, including children, with disabilities have the same right to privacy as everyone else, including privacy in respect of personal, health and rehabilitation information.</p>
<p><b>Family responsibilities and support</b></p> <p><b>Article 18</b> – both parents have equal responsibilities for their children and should have children’s best interests as their primary concern. States must provide assistance, support and services to help parents bring up their children.</p>	<p><b>Article 23</b> – States must provide appropriate assistance to parents with disabilities to help them care for their children. Children with disabilities have equal rights to family life and States must provide early information, services and support to children with disabilities and their families to prevent concealment, abandonment, neglect and segregation.</p>
<p><b>Protection from all forms of violence</b></p> <p><b>Article 19</b> – children have the right to protection from all forms of violence, neglect, exploitation and abuse, and States must take all appropriate measures to protect them from such violence.</p>	<p><b>Article 16</b> – affirms the right to protection from violence, and requires States to provide forms of support to people with disabilities to help them avoid violence and abuse, and it must be accessible and appropriate to children with disabilities, as well as gender sensitive. All protection services must be age, gender and disability sensitive. States must introduce child-focused legislation and policies to ensure that violence against children with disabilities is identified, investigated and prosecuted where appropriate.</p>

*continued opposite*

**Table. Relationship between the UNCRC and the CRPD** *continued*

<b>UNCRC</b>	<b>CRPD</b>
<p><b>Alternative care</b></p> <p><b>Article 20</b> – children who cannot live with their family are entitled to protection and assistance by the State, and efforts must be made to provide stability for children and to show respect for their ethnic, religious, cultural and linguistic background.</p> <p><b>Article 21</b> – where adoption is recognised or permitted by a State, they must ensure that appropriate safeguards exist, and that the best interests of the child are the paramount consideration.</p>	<p><b>Article 23</b> – where the family cannot care for a child with a disability, States must “undertake every effort” to avoid institutionalisation: alternative care should be sought within the wider family or in the community in a family setting.</p> <p>States must ensure the rights and responsibilities of people with disabilities to guardianship, wardship, trusteeship and adoption of children. In all cases, the best interests of the child must be paramount.</p>
<p><b>Refugee children</b></p> <p><b>Article 22</b> – children seeking refugee status must receive appropriate protection and assistance to enable them to realise their rights.</p>	

*continued overleaf*

**Table. Relationship between the UNCRC and the CRPD** *continued*

UNCRC	CRPD
<p><b>Children with disabilities</b></p> <p><b>Article 23 – leading article in the UNCRC for the rights of children with disabilities.</b> Children with disabilities are entitled to a life in conditions that enable them to become independent and participate actively in their community. They are entitled to special care, which should be free of charge, wherever possible, and which ensures access to education, training, healthcare, rehabilitation, and preparation for employment and recreation. These services should be provided in a way which enables the child to achieve the fullest possible integration and development. States should also promote international cooperation to enable developing countries to improve their capacities and experience.</p> <p>(See following boxes for details on health and education rights.)</p>	<p><b>The CRPD builds on Article 23 of the UNCRC by the introduction of obligations to remove the barriers that prevent the social inclusion and independence of people with disabilities, including children, for example:</b></p> <p><b>Article 3</b> – establishes a general principle that people, including children, with disabilities have the right to full and effective participation and inclusion in society.</p> <p><b>Article 9</b> – requires States to make the physical environment, transport, information and communications accessible to people with disabilities.</p> <p><b>Article 19</b> – the right to live in the community, and to access to community-based services and facilities to support their community living.</p> <p><b>Article 20</b> – requires States to support personal mobility for people with disabilities.</p> <p><b>Article 26</b> – requires States to provide comprehensive habilitation and rehabilitation services that begin at the earliest possible age, and which support participation and inclusion in the community and all aspects of society.</p>

*continued opposite*

**Table. Relationship between the UNCRC and the CRPD** *continued*

<b>UNCRC</b>	<b>CRPD</b>
<p><b>Health and prevention of disability</b></p> <p><b>Article 24</b> – the right to the best possible health and access to healthcare services. Specifically, States must take the following measures:</p> <ul style="list-style-type: none"> <li>• Diminish child mortality.</li> <li>• Ensure provision of medical care with emphasis on primary care.</li> <li>• Combat disease and nutrition, including through provision of food, clean drinking water, and taking account dangers of environmental pollution.</li> <li>• Ensure pre- and post-natal care for mothers.</li> <li>• Ensure access to education in child health and nutrition, hygiene and environmental sanitation and prevention of accidents.</li> <li>• Abolish harmful traditional practices.</li> <li>• Encourage international cooperation.</li> </ul>	<p><b>Article 25</b> – States must ensure the right to the best possible standard of, access to, and quality of healthcare, without discrimination on the grounds of disability. Health services must include access to sexual and reproductive health programmes, and services to minimise and prevent further disabilities. Services must be provided as close as possible to people’s homes.</p>
<p><b>Review of treatment and care</b></p> <p><b>Article 25</b> – right of children who have been placed for care, protection or treatment to regular reviews of their treatment and all other aspects of their care.</p>	

*continued overleaf*

**Table. Relationship between the UNCRC and the CRPD** *continued*

UNCRC	CRPD
<p><b>Adequate standard of living and social protection</b></p> <p><b>Article 26</b> – right to benefit from social security.</p> <p><b>Article 27</b> – right to an adequate standard of living for physical, mental, spiritual, moral and social development. While parents have primary responsibility to provide the conditions for the child’s development, States must take appropriate measures to support parents, including through programmes for nutrition, clothing and housing. States must also introduce all appropriate measures to provide recovery of maintenance when parents separate.</p>	<p><b>Article 28</b> – right of people, including children, with disabilities to an adequate standard of living including food, clothing and housing and to continuous improvement of living conditions. States must take appropriate steps to secure this right without discrimination on the ground of disability.</p> <p>States must recognise the right of people with disabilities to social protection without discrimination and take appropriate steps to ensure access to:</p> <ul style="list-style-type: none"> <li>• clean water on an equal basis with others</li> <li>• assistance for disability-related needs</li> <li>• social protection and poverty reduction programmes, particularly for women and girls</li> <li>• help with disability-related expenses</li> <li>• access to public housing.</li> </ul>

*continued opposite*

**Table. Relationship between the UNCRC and the CRPD** *continued*

UNCRC	CRPD
<p><b>Education</b></p> <p><b>Article 28</b> – right to education on the basis of equality of opportunity. States must:</p> <ul style="list-style-type: none"> <li>• make primary education compulsory and free to all</li> <li>• make secondary school available and accessible to every child and take measures to make it free</li> <li>• make higher education accessible to all on basis of capacity</li> <li>• make vocational information available and accessible to all children</li> <li>• take measures to increase attendance and reduce drop-outs.</li> </ul> <p>All appropriate measures must be taken to ensure that school discipline respects children’s dignity and complies with other rights in the UNCRC, and States must encourage international cooperation.</p> <p><b>Article 29</b> – education must be directed to the development of children to the fullest potential, respect for human rights, respect for the child’s parents and their values, the values of their own and others’ societies, preparation of the child for life in a free society and respect for the natural environment.</p>	<p><b>Article 24</b> – affirms the right of people with disabilities to inclusive education, at all levels, without discrimination and on the basis of equality of opportunity. States must ensure that children with disabilities:</p> <ul style="list-style-type: none"> <li>• are not excluded from the general education system and can access inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live</li> <li>• are provided with reasonable accommodation of their needs</li> <li>• receive the support they need within the general education system</li> <li>• are provided with individualised support measures, consistent with full inclusion.</li> </ul> <p>States must also take measures to enable people with disabilities to participate equally in education and their communities by supporting learning of all alternative forms of communication, and enabling deaf, blind and deafblind children to learn in the most appropriate languages and modes and in environments that maximise their development.</p> <p>The education system must enable people with disabilities to achieve the full development of their personality, talents, creativity and mental and physical abilities, a sense of dignity and self-worth, respect for human rights and effective participation in society.</p>

*continued overleaf*

**Table. Relationship between the UNCRC and the CRPD** *continued*

UNCRC	CRPD
<p><b>Respect for language and culture</b></p> <p><b>Article 30</b> – children must not be denied the right to enjoy their own culture, practise their religion and use their own language.</p>	<p><b>Article 30</b> – people with disabilities are entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign language and deaf culture.</p>
<p><b>Play, leisure, culture and sport</b></p> <p><b>Article 31</b> – right to rest, leisure, play and recreation activities appropriate to the age of the child and to participate in cultural life.</p>	<p><b>Article 30</b> – right of people with disabilities, including children, to take part on an equal basis with others in cultural life through provision of accessible cultural materials and places of cultural performances and services. States must take appropriate measures to enable people with disabilities to develop their creative potential. They must also ensure that children with disabilities have equal access with other children to play, recreation and leisure, and to both mainstream and disability-specific sporting activities, including in the school system.</p>
<p><b>Protection from exploitation and harm</b></p> <p><b>Article 33</b> – States must take measures to protect children from both illicit use of, and involvement in the production and trafficking of, drugs.</p> <p><b>Article 34</b> – States must take all necessary measures to protect children from all forms of sexual exploitation and sexual abuse.</p> <p><b>Article 36</b> – States must protect children from all other forms of exploitation harmful to their wellbeing.</p>	

*continued opposite*

**Table. Relationship between the UNCRC and the CRPD** *continued*

UNCRC	CRPD
<p><b>Freedom from torture and cruel, inhuman and degrading treatment</b></p> <p><b>Article 37</b> – no child must be subjected to torture, or cruel, inhuman or degrading treatment.</p> <p>No child must be deprived of liberty arbitrarily and any detention must be only as a measure of last resort and for the shortest appropriate period of time. Children deprived of liberty must be treated with humanity and respect for dignity, and separated from adults. They must have prompt access to legal and other appropriate assistance, and the right to challenge the legality of their deprivation of liberty.</p>	<p><b>Article 15</b> – affirms the right to freedom from torture, and cruel, inhuman and degrading treatment for people with disabilities, including children, and adds that they must not be subjected to medical or scientific experimentation without their consent. States must take all effective measures to prevent people with disabilities, on an equal basis with others, experiencing such treatment.</p> <p><b>Article 17</b> – people with disabilities have the right to respect for physical and mental integrity on an equal basis with others.</p> <p><b>Article 14</b> – States must ensure that people with disabilities enjoy the right to liberty on an equal basis with others and where they are deprived of liberty, they must have human rights guarantees on an equal basis with others. The existence of a disability shall in no case justify a deprivation of liberty.</p>
<p><b>Situations of risk, conflict and humanitarian emergencies</b></p> <p><b>Article 38</b> – States must take all feasible measures to protect children in situations of armed conflict.</p> <p>(See also Optional Protocol on Children and Armed Conflict.)</p>	<p><b>Article 11</b> – States must take all necessary measures to ensure the protection and safety of people, including children, with disabilities in situations of armed conflict, humanitarian emergencies, and occurrence of natural disasters.</p>

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**Table. Relationship between the UNCRC and the CRPD** *continued*

UNCRC	CRPD
<p><b>Recovery and reintegration</b></p> <p><b>Article 39</b> – States must take all appropriate measures to promote the recovery and reintegration of children who have experienced violence, neglect, exploitation, torture, punishment or armed conflict. These measures must foster the health, self-respect and dignity of the child.</p>	<p><b>Article 16</b> – States must take all appropriate measures to promote the physical, cognitive and psychological recovery rehabilitation and reintegration of people with disabilities who have experienced exploitation, violence and abuse, including in the provision of any care services. These measures must foster the health, self-respect and dignity of the person, and take account of the specific needs of women and children.</p>
<p><b>Access to justice</b></p> <p><b>Article 40</b> – right of the child accused of a crime to be treated with respect and dignity and in accordance with his or her age, and the importance of promoting reintegration.</p> <p>Every accused child is entitled to:</p> <ul style="list-style-type: none"> <li>• be presumed innocent until proved guilty</li> <li>• be informed promptly of any charges and to have legal representation</li> <li>• have access to a fair hearing</li> <li>• not be compelled to give evidence</li> <li>• be able to appeal</li> <li>• to have a free interpreter where necessary</li> <li>• to have privacy respected.</li> </ul> <p>States must establish separate criminal justice systems for children, a minimum age of criminal responsibility, and measures for diverting children from the courts. A range of dispositions must be available as alternatives to custody, including probation, foster care and education programmes that promote children’s wellbeing and are appropriate to their circumstances and offence.</p>	<p><b>Article 13</b> – States must ensure that people with disabilities have access to justice on the same basis as others. Children with disabilities must be provided with disability- and age-appropriate support to enable them to participate at all stages in any legal proceedings affecting them. Staff working in the justice system must have appropriate training to enable them to ensure effective justice for people with disabilities.</p>

## General principles

### The key issues

The Committee on the Rights of the Child has identified four separate articles of the UNCRC that are not only rights, but also general principles to be considered in the implementation of all other rights. These are: non-discrimination, best interests, the right to life, and the right to express views and have

them taken seriously. Similarly, there is an article in the CRPD that establishes the fundamental principles which must be applied in its overall implementation. These principles correspond to a large degree with the underlying principles of the UNCRC. However, they add some additional dimensions to address the specific challenges and barriers faced by people with disabilities, including children. Some of these principles are also further elaborated and strengthened in separate articles in the CRPD.

### The rights

#### UN Convention on the Rights of the Child

**Article 2** – non-discrimination

**Article 3** – best interests of the child

**Article 6** – child’s right to life and maximum survival and development

**Article 12** – respect for the views of the child

#### Convention on the Rights of Persons with Disabilities

**Article 3** – general principles – respect for dignity, autonomy, freedom to make

choices, independence, non-discrimination, participation, respect for difference, equality of opportunity, accessibility, equality between men and women, respect for the evolving capacities of children and preservation of identity

**Article 5** – equality and non-discrimination

**Article 7** – children with disabilities

**Article 10** – right to life

**Article 17** – protecting the integrity of the person

### The right to non-discrimination

*“Since I’ve been in a wheelchair, people do not treat me the way they used to before. People do not respect me.”*

(Child in South Africa<sup>44</sup>)

*“Traditional attitudes and beliefs have created the world we live in. And we exist, we are here, but people just don’t accept that.”*

(Child in Nepal<sup>45</sup>)

The UNCRC was the first ever human rights treaty to recognise and specify disability as a ground for protection from discrimination. The Committee on the Rights of the Child has acknowledged that children with disabilities are one of the groups of children most vulnerable to discrimination. Social stigma, fear, over-protection, negative attitudes and prevailing prejudices are strong in many communities, leading to marginalisation, exclusion and violence. However, despite the

## Cultural traditions can serve to discriminate<sup>46</sup>

In South Korea, many children suffer ostracism. The Confucian influence teaches reverence for bloodlines and people are very conscious of how others view them. A baby born with physical or intellectual disabilities is considered to have tainted blood, so families often try to hide them. Many parents prefer to send such children to shelters rather than care for them at home, and some children are abandoned to state institutions.

growing body of evidence as to the scale of discrimination faced by children with disabilities, very few governments have yet introduced legislation to protect against discrimination on grounds of disability.

The Committee on the Rights of the Child suggests a range of measures to prevent and eliminate all forms of discrimination against children with disabilities.<sup>47</sup>

- Include **disability as a forbidden ground for discrimination in constitutional provisions** on non-discrimination and/or include specific prohibition of discrimination on the grounds of disability in specific anti-discrimination laws or legal provisions.
- Provide for **effective remedies in case of violations** of the rights of children with disabilities, and ensure that those remedies are easily accessible to children with disabilities and their parents and/or others caring for the child.
- Conduct **awareness-raising and educational campaigns** targeting the public at large and specific groups of professionals with a view to preventing and eliminating de facto discrimination against children with disabilities.
- Pay **particular attention to girls with disabilities** by taking the necessary

measures to ensure that they are well protected, have access to all services and are fully included in society.

Article 3 of the CRPD also establishes non-discrimination and equality of opportunity, including between men and women, as general principles. In addition, Article 5, 'Equality and non-discrimination', introduces specific measures which elaborate and strengthen the provisions in the UNCRC:

- It explicitly requires that governments prohibit all discrimination on the basis of disability and guarantee **effective legal protection** for children with disabilities.
- It introduces the concept of '**reasonable accommodation**'. Reasonable accommodation means that necessary and appropriate adaptations must be made to ensure that people with disabilities can enjoy their rights on an equal basis with others, as long as they do not impose a disproportionate burden. For example, a health clinic may have steps at the entry, and doors that are too narrow for a wheelchair to go through. If the authorities refused to adapt the building by building a ramp and adjusting the doors, this would be discrimination against children with disabilities by failing to make reasonable

## Double jeopardy for girls with disabilities<sup>48</sup>

Girls with disabilities experience a double jeopardy. Many girls are at greater risk of becoming disabled because of neglect and certain forms of abuse and harmful practices such as early marriage and female genital mutilation. Once they have a disability, they are less likely to have access to healthcare or to educational or vocational rehabilitation. In

Nepal, for example, in 1995 the long-term survival rate for boys who had polio was twice that for girls, despite the fact that males and females have an equal chance of surviving the disease. And in a rehabilitation hospital in Kathmandu, a serious under-representation of girls was identified as major cause for concern.

accommodation. Equally, failure to provide sign-interpreters for a deaf child in hospital would constitute a failure to make reasonable accommodation, leading to the child being discriminated against in his or

her right to equal quality of healthcare. On the other hand, in a small primary school located on two floors, it may be considered to be disproportionate to require a lift to be built. However, failure to seek to

## Anti-discrimination legislation in the United Kingdom<sup>49</sup>

Under the **UK's Disability Discrimination Act**, an employer discriminates against a disabled person if two conditions are met: "(a) he fails to comply with a section 6 duty [to make reasonable adjustments] imposed on him in relation to the disabled person; and (b) he cannot show that his failure to comply with that duty is justified".

Section 6 (4) of the Act lists key factors that must be considered in determining whether it is reasonable for an employer to have to take a particular step in order to comply with the duty to make reasonable adjustments:

- "(a) The extent to which taking the step would prevent the effect in question;
- (b) The extent to which it is practicable for the employer to take the step;
- (c) The financial and other costs which would be incurred by the employer in taking the step and the extent to which taking it would disrupt any of his activities;
- (d) The extent of the employer's financial and other resources;
- (e) The availability to the employer of financial or other assistance with respect to taking the step."

organise classes to enable a child who was a wheelchair user to have lessons on the ground floor may well be discriminatory. In other words, duty-bearers cannot simply take no action.

- It establishes recognition that positive measures introduced to enable children with disabilities to achieve equality are not considered to be discrimination. For example, giving blind children extra time in public examinations is a form of **acceptable positive discrimination**, because it takes longer to read Braille than printed script. Similarly, higher levels of social protection or social security benefits for children with disabilities are acceptable because they may have higher costs associated with their disability. The Committee on the Rights of the Child has stressed that Article 2 of the UNCRC should not be interpreted to mean that all children should be treated the same, as long as any differentiation is in the best interests of the child. The provision in Article 5 of CRPD lends formal legal force to this interpretation, but must also be understood in line with the best interests of the child (see next paragraph).

### **Best interests of the child**

Article 3 of the UNCRC introduces a provision that the best interests of the child must be a primary consideration in all actions affecting children. It applies not only to actions affecting individual children, such as in a care placement, but also to children as a body, for example, in the development of disability services. It applies to private institutions as well as to public bodies.

The broad nature of Article 3 is intended to cover all aspects of care and protection for children in all settings. It needs to inform the legal framework for protecting the rights of children with disabilities, as well as the decision-making processes concerning them. Article 3 should be the basis on which programmes and policies are developed, and it should be taken into account in every service provided for children with disabilities and any other action

affecting them. The best interests of the child also need to inform the practice of institutions and other facilities that provide services for children with disabilities. They must have the safety, protection and care of children as their primary consideration, and this principle should outweigh any other consideration, for example, when allocating budgets.

Article 7 of the CRPD reaffirms this principle, emphasising its application to children with disabilities, and that the principle must apply to the implementation of all provisions of the CRPD as well as those of the UNCRC.

### **Right to life and maximum survival and development**

The right to life is often violated for children with disabilities, both directly and indirectly. In some communities, children with disabilities are abandoned and left to die. Parents who either kill or allow a disabled child to die often attract far lower penalties than if the child were not disabled. In institutions in some countries, children with disabilities are denied food and warmth in order that they will die. In addition, there is a widespread practice in health systems of making a decision that the quality of life of a child with a disability does not justify his or her continued existence and accordingly they are denied either resuscitation, or food and fluids. These decisions to allow a child to die are justified in the best interests of children.

Systematic evidence of the violation of the right to life of children with disabilities is difficult to gather – data is not collected on the failure to protect the lives of such children. Rather, their deaths will be recorded as arising from their disability rather than medical neglect or inaction. Evidence is, therefore, inevitably anecdotal. However, NGOs working in the field consistently document not just examples of children whose lives have not been protected, but evidence that such judgements are informed by policies which consider severely disabled children as of insufficient value to justify proactive intervention to protect life.

## Children with disabilities are allowed to die<sup>50</sup>

A letter sent from a disabled peoples' organisation in Gambia states that "children with severe disabilities do not survive childhood. The lack of rehabilitation facilities coupled with fear of the difficult responsibility of rearing and bringing up an invalid results in negligence and eventual death of these children". In South Africa, a complaint was filed with the Human Rights Commission concerning a number of children who died and for whom the death certificates recorded the cause of death as disability.

A previous president of the International Association of Bioethics has commented, in respect of Down's Syndrome babies: "We may not want a child to start on life's uncertain voyage if the prospects are clouded. When this can be known at the very early stage of the voyage, we may still have a chance to make a fresh start. This means detaching ourselves from the infant who has just been born. Instead

of going forward and putting our efforts into making the best of the situation, we can still say no and start again from the beginning."<sup>51</sup>

A survey published in 2000 in the medical journal, *The Lancet*, indicated that in the Netherlands, half the doctors reported administering drugs to end the lives of babies with an incurable disease, and in the USA, a

## Discrimination against Down's Syndrome babies in the UK<sup>52</sup>

A report commissioned by the Down's Syndrome Association in the UK in 1999 cites the following experiences of abuse in respect of the value of the life of a disabled child:

- A mother was told that people would look away from her baby in horror.
- A mother was told her baby would be good for nothing.
- Health professionals describing the babies as 'happy idiots'.
- A six-month-old baby was given no pain relief after heart surgery because "Down's children don't feel pain".
- Without examining her child, a consultant told a mother in front of students that the child's heart condition was inoperable.
- Parents were told to go away and have another baby.

Director of Pediatric Surgery created a formula to measure the quality of life of babies with spina bifida:  $NE \times (H+S) = \text{Quality of life}$ . NE is the natural intellectual and physical endowment of the child, H is the support from home and S the quality of social services available. This formula was applied in making decisions to withhold treatment from 24 babies, who eventually died.

The UNCRC recognises the right to life of every child. It also places an obligation on governments to ensure, to the maximum extent possible, the survival and development of the child. The Committee on the Rights of the Child, in the General Comment on children with disabilities, urges governments to undertake all the measures required to put an end to practices that deny the right to life, including raising public awareness, setting up appropriate legislation and enforcing laws that ensure appropriate punishment of all those who directly or indirectly violate the right to life, survival and development of children with disabilities.

Article 10 of the CRPD reaffirms the right to life (although, because it does not exclusively address children, it does not deal with the right to survival and development). It strengthens the recommendations of the Committee on the Rights of the Child by requiring governments to introduce measures to protect the right to life without discrimination. In addition, in Article 25, it stresses that denying people with disabilities healthcare, health services or food or fluids, in ways that would lead to their death, is discriminatory and must be prohibited. Non-discrimination in respect of the right to life also requires that parents or others who abandon a child with disabilities, leading to their death, be treated on the same basis as if they had abandoned a non-disabled child. Governments should also provide support and services to parents to help them provide appropriate care for the child (see also the section on the right to family life, on page 91, setting out the obligation on governments to

support families). To prevent neglect and death in institutions, governments must introduce better training and screening of staff, minimum standards, regulations, regular inspections, complaints mechanisms and review processes.

### Right to participation

*“We need to believe in ourselves and challenge negative opinions by showing how able we are.”*

*“We need to be arguing for our own rights – not just rely on non-disabled adults to do this on our behalf.”*

*“Disability is in the eyes of society. It is not in our eyes. If provided with opportunities, we can prove our worth.”*

(Quotes from children with disabilities in Nepal<sup>53</sup>)

Article 12 of the UNCRC establishes that all children capable of forming a view have the right to express their views on all matters of concern to them, and to have them given due weight in accordance with age and maturity. In addition, Article 12 provides that the child shall be afforded the right to be heard in any judicial or administrative proceedings affecting the child. This principle establishes one of the fundamental values of the Convention. Although many countries have begun to explore approaches to implementing Article 12, it remains the case that children with disabilities are rarely provided with such opportunities. Initiatives such as school councils, youth forums, children’s parliaments and children’s clubs, as well as consultative processes to elicit children’s views, too often ignore children with disabilities. In addition, these children experience particular difficulties in getting their voices heard in judicial and administrative proceedings. This is partly because little effort is made to accommodate their needs, and partly because of prejudicial attitudes which fail to recognise the capacities of children with disabilities to have views or express them.

The Committee on the Rights of the Child has stressed that children with disabilities are entitled to participate on an equal basis with other children; practical measures must be introduced to facilitate their participation, including availability of transport, accessible information, assistive devices, communication aids and interpreters. It also makes clear that Article 12 applies to children as individuals, as

a group and as a constituency, whether in the context of family, school, healthcare, the courts or child protection, and in all local and national policy-making contexts.<sup>54</sup> The CRPD lends strength to this emphasis by introducing an explicit obligation on governments to provide children with disability- and age-appropriate assistance to realise their right to participation.

## Hints and tips from young disabled people on communicating<sup>55</sup>

Don't blame us or have a go at us.

We do have feelings.

We're just like other children.

Show respect, and don't patronise us.

Take your time and make sure you understand.

Talk directly to us, not just to our parents or our carers.

Don't be scared to ask questions.

Really listen and understand.

Make sure you really understand us because I have seen carers, parents and other people who didn't even know or can't be bothered to find out how we say yes or no. Sometimes people say later, later, because they think we're asking for attention.

Keep calm and get on with it.

Don't be scared.

Learn from young people.

Show an interest in us, make it more than just a job.

## South African children identify how they can bring about change<sup>56</sup>

Children in South Africa identified the following factors as necessary for achieving change:

- becoming self-advocates in order to change people's mindset
- being assertive in order to be able to achieve
- keeping themselves informed about their rights in order to challenge violations
- recognising their own strengths and talents and their capacity to utilise those talents.

Article 17 of the UNCRC stresses the right of children to information, access to which is a prerequisite for effective participation. Children cannot express views or make informed choices without information. However, children with disabilities are often precluded from such access. Very significant numbers in the developing world are not in school, and the means of providing information – television, radio, the Internet and written materials – are often not available to them. Accordingly, Article 21 of the CRPD introduces additional obligations on governments to ensure that children with disabilities are able to seek and impart information on an equal basis with other children and through all communication means of their choice. This will involve:

- providing information in accessible formats and technologies appropriate to different kinds of disabilities, without unreasonable delay or additional cost to the child
- accepting and facilitating the use of sign language, Braille, augmentative and alternative communication, and modes and formats of communication of their choice
- urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for people with disabilities.

*“One of the things I think is important is to inform people about this. It’s easier to make good decisions for these children if you’ve got all the facts. It can also help them in school and life generally, because they then will get better treatment and will be more accepted in society. As to Norway, we have the resources to make this work, but in countries that don’t have that, it’s important to make the governments... follow child rights for disabled children. Let them know someone’s fighting their cause.”*

(Girl, 17, Norway, Voices of Youth website)

### **Right to respect for integrity, dignity, and autonomy**

People with disabilities are traditionally denied the right to independence and personal and

physical integrity. Decisions are commonly made on their behalf. They are also denied opportunities for independence, and medical and other interventions are frequently made without their consent. They are treated in a manner which is at best, paternalistic and protective, at worst, abusive and degrading. Article 23 of the UNCRC insists that conditions are provided that ensure the dignity of children with disabilities. Articles 3 and 17 of the CRPD go further and explicitly introduce the right of people with disabilities to autonomy, independent decision-making and respect for their physical and personal integrity. These principles are of direct relevance to children with disabilities, but need to be understood within the context of the relationship between parents and children.

Article 5 of the UNCRC affirms that parents have rights and responsibilities to provide direction and guidance to their children in recognition of the latter’s need for care and protection. However, it also emphasises that any direction and guidance must be aimed at the exercise by the child of their rights, in accordance with their evolving capacities. This means that:

- parental rights exist only in order to protect and promote children’s rights. Accordingly, parents must act in ways consistent with the principles of the UNCRC and, in respect of children with disabilities, with the CRPD.
- parental rights extend only for as long as the child is unable to exercise those rights for herself or himself. They must take account of the evolving capacities of the child to exercise those rights for herself or himself. By implication, as soon as children have the capacity, then parental rights recede.

Children with disabilities experience far greater difficulties in gaining recognition of their capacities for independent decision-making. They are commonly over-protected, infantilised and denied opportunities for their emerging autonomy. This over-protection limits their capacity to develop fully, and can undermine confidence and deny them respect

for privacy and personal integrity. The CRPD balances the importance of addressing parents' legitimate protective responsibilities for children with disabilities, who lack capacity for independent decision-making, with their obligation to respect children's emerging capacities to exercise their own rights.

Article 3, while introducing the principle of autonomy and independence, also includes a requirement to respect the evolving capacities of children with disabilities. In doing so, it affirms the principle embodied in the UNCRC and applies it to address the particular situation of children with disabilities.

### Advocacy tips on general principles

- **Check the constitution and legislation. Does it include a specific prohibition on discrimination on grounds of disability? If not, draw the government's attention to its obligations under the CRPD.**
- **Set up a database to gather and record examples of discrimination on grounds of disability. This can be used to inform your advocacy.**
- **Undertake a review of legislation affecting children with disabilities to assess whether it addresses their best interests. Advocate for the explicit inclusion of the best interests principle in all relevant legislation and policies.**
- **Undertake research with children with disabilities on their capacities. Are they over-protected? Can they be supported to take greater responsibility for their own decisions? What needs to change to enable this to happen?**
- **Support the development of spaces where children with disabilities can share their concerns and create messages to communicate to policy-makers on barriers to the realisation of their rights.**
- **Find out the policies of health authorities and any associations of health professionals on the right to life of children with disabilities. Gather evidence of cases where the right to life is denied and use it to campaign for changes in the law, policy and practice.**

## Right to family life

### The key issues

The family is usually the ideal environment for a child to grow up in, and it plays a vital role in ensuring the wellbeing of children. When a child is removed from its protective care, or the family is weakened or undermined in its capacity to provide that care, the cost for children is high.

To date, too little attention has been given to introducing measures to ensure that the right to family life is upheld for children with disabilities, or to providing the support that families need to ensure these children's protection. In many societies, prejudice, ignorance and discrimination, combined with a lack of community-based support or social security provisions, undermine families' capacities to provide appropriate care and protection for a child with a disability. The

stigma associated with disability can lead to children being hidden within the home, their existence denied and opportunities for the realisation of their rights extremely limited. It also contributes to the disproportionate number of children with disabilities being brought up in single-parent households – with fathers often abandoning the family when a child is born with an impairment, leaving the mother to cope alone. In some societies, the extended family will also withdraw support, further isolating the mother and undermining her capacity to provide adequate care for the child.

In some societies, there is active encouragement by professionals for families to abandon their children into institutions. Once children are placed in an institution, they often remain there for the whole of their lives. They are effectively imprisoned, despite having committed no offence, and without a time limit or right to appeal. Children in institutions face the violation of many other rights – access to education and healthcare, social inclusion, protection from violence, play, opportunities for friendships – and sometimes, even the right to life. Despite growing awareness of these violations, the number of children in institutional care remains high. For example, in central and eastern Europe and the Baltic states, the number of children with disabilities in institutions more than doubled after the transition from communism. By the end of the 1990s, nearly one million children (1%) were living in institutions in the 27 countries of the Central and Eastern Europe/Commonwealth of Independent States; nearly one-third of them were children with disabilities.<sup>57</sup> Children with psychosocial disabilities are also vulnerable to being detained without the right to challenge the decision.

## The rights

### **UN Convention on the Rights of the Child**

**Article 9** – separation from parents

**Article 18** – parents' joint responsibilities assisted by the state

### **Convention on the Rights of Persons with Disabilities**

**Article 19** – living independently

**Article 23** – respect for home and the family

## **Non-discrimination**

By emphasising equal rights with respect to family life, the CRPD makes it clear that it is not acceptable to place a lower priority on the protection of family life for children with disabilities. The importance of family is the same for every child, irrespective of disability. In this regard, it is not adding any new principle or obligation to the UNCRC. However, it does spell out that the principle of non-discrimination extends to family life for children with disabilities, and reaffirms the obligation to respect this right.

## **Support for families**

In its preamble, the UNCRC emphatically endorses the family as the natural environment for children, and recognises the need for children to grow up within a family in “an atmosphere of happiness, love and understanding”. It emphasises that families should be provided with all the necessary protection and assistance to enable them to fulfil their responsibilities. In support of this

## Denying the right to family life<sup>58</sup>

A Romanian mother, when told that her child was autistic, was advised to place him in an institution, because he would never improve, would bring no joy and would destroy the family. She should therefore leave him in an institution and forget his existence. Despite this recommendation, she chose to keep the child. Unfortunately, however, part of the prediction proved accurate because of deeply ingrained prejudice facing children with disabilities. Her husband left her, unable to cope with the stress. Her extended family was reluctant to have

anything to do with the child. His younger brother faced frequent bullying and taunts from friends about his 'stupid' older brother, and eventually resorted to denying his existence. On transferring to high school, the younger boy found that, on his education notes, it stated that he had a brother with a severe learning disability. The mother, drawing on the experiences of others, was convinced that this would damage her younger son's chances of getting a university place.

## Parental neglect and abuse of children with disabilities<sup>59</sup>

- A Palestinian teenager was kept in a barred cage with only bread and water to eat. She was hosed down to keep her clean. Other mothers threatened their children that she would be let loose to punish them. After 14 years of being tethered with sheep, she made sheep-like noises.
- In Zambia, a disabled child was locked inside for 15 years because his parents were ashamed of having him. The child was never given a bath and was contaminated with faeces.
- In Nigeria, a five-year-old girl with cerebral spinal meningitis as well as learning

difficulties and physical impairments was locked into a specially built hut on her father's farm for two years. Her stepmother refused to let her into the house because she was doubly incontinent. She ate the hay she slept on and emptied her bowels into the grass she chewed. Her plight was discovered because the father approached street cleaners for any left-over scraps, which they believed were to be given to a puppy. The child's father was then prosecuted and imprisoned for nine months, but the stepmother received no punishment because she was related to the magistrate.

recognition, it includes a number of provisions that reinforce the right of children to family life. All the rights in the UNCRC apply to all children without discrimination on any grounds, including disability. These provisions therefore apply to children with disabilities on an equal basis with all other children. They place obligations on governments to provide support for parents to strengthen their capacities to care for their children. The General Comment on children with disabilities emphasises that children are best cared for within their families,

and to enable families to provide effectively for children with disabilities, recommends:

- education of parents and siblings on causes of disability and each child's unique needs
- psychological support
- help with learning a common language for the family, such as sign language
- material support including allowances and necessary equipment
- mobility support
- respite care and daycare facilities.

## Tackling ignorance to reduce risk of impairments<sup>60</sup>

A number of disabilities are linked to preventable causes – for example, poor nutrition, poor medical care during pregnancy, high levels of alcohol consumption during pregnancy. In a kindergarten in a village in Mongolia, the cook has an approach from which much can be learned and shared. She not only

cooks nutritious school meals from ingredients she grows in the kindergarten grounds, she also gives parents recipes for nutritious meals, and gives them training and advice on how to eat healthily, which vegetables to grow and how to make sure their families have a balanced and nutritious diet.

## Parents' needs<sup>61</sup>

In South Africa, DICAG, an NGO working with parents of children with disabilities, argues that there are five elements needed for parent empowerment so that they, in turn, can fight for the rights of their children:

- establishing mutual respect between parents and professionals which accepts that parents, like professionals, have qualities and skills
- acknowledging and recognising families' needs and strengths
- providing information as an essential foundation for making rational and informed choices
- creating opportunities for exposure and social contacts
- supporting the development of economic independence of mothers through early childhood development facilities, basic adult education, and training and skills development for self-employment.

The CRPD introduces specific provisions which take account of the nature of rights violations experienced by children in relation to family life, and it places additional obligations on governments to take the necessary action to address these rights violations. Although rights with respect to family life apply to every child on the same basis, the nature of support needed to protect that right will differ according to the individual child. The CRPD recognises that children with disabilities are often abandoned, concealed or neglected because parents do not understand the nature or causes of disability, or lack the knowledge, skills or capacity to provide the care the child needs. Accordingly, it introduces new obligations to provide families with “early and comprehensive information, services and support”:

- The emphasis on **early provision** is important. The sooner a disability is recognised or diagnosed, the sooner the child can start receiving the help she or he needs. For example, the development of a deaf child will be impeded if no one recognises that she or he is deaf. The child will lose out, for example, on communication, socialising, forming friendships, play and learning.
- Parents need **information** about the causes and nature of the impairment, whether there is any treatment necessary, and how to help the child accommodate or compensate for the impairment. In the case of the deaf child, for example, family members and the child need early provision of help with learning signing in order to facilitate communication. Information is vital to help the parent understand how to provide the best possible care for their child, and to recognise both the potential of the child and how to help them realise it. Many parents lack the skills, knowledge and resources to interact effectively with schools and healthcare services, while on the part of those services, too, there is often a lack of commitment to reach out to parents. Schools can organise meetings of parents to share with them information about how they are teaching the

child, and updates on the child’s progress in order to help the parent to understand the child’s education. Many schools argue that this type of investment in parents is of equal importance to the education of children with disabilities as the direct learning the children receive in school.

- Parents also need to be **aware of their child’s rights** – ie, to education, to be treated on an equal basis with other children, to play, to friendships and to social inclusion. Children with disabilities have the right to express their views and have them taken seriously, including within the family. They also have the right to be involved in decisions that affect them and to take responsibility for decisions they are competent to make for themselves. Parents and other carers of children with disabilities can often be over-protective, and fail to make space for their children to acquire skills, become more independent and learn to manage risks. Parents need to be supported and encouraged to ensure that all these rights are respected. They also have a responsibility to advocate for their child’s rights when they are not being fulfilled by governments and others. This may involve, for example, challenging a school’s refusal to admit a child with a disability, or a failure to provide mobility aids or devices, or the failure to adapt public buildings to make them accessible.
- Parents need **services**, such as different forms of respite care, care assistance in the home, community-based daycare facilities, mobility devices, adaptations to the home, appropriately designed furniture, as well as help with laundry and consumable supplies.

### **Alternatives to institutionalisation**

(see also ‘Right to justice and liberty’ page 134.)

The UNCRC does not make any explicit reference to institutionalisation for children with disabilities or to the need for alternatives, although the General Comment makes it clear that the Committee on the Rights of the Child is concerned about the continued use of

institutions as a placement option for children with disabilities in many countries. The Committee recognises that, in general, institutions provide a much inferior quality of care and render children more vulnerable to violence and abuse. It recommends that they should only be used as a measure of last resort, when it is absolutely necessary and in the best interests of the child. It further recommends that existing institutions should be transformed, with a focus on smaller facilities organised around the rights and needs of the child, that national standards should be introduced, and that there should be rigorous screening and monitoring procedures to ensure effective implementation of these standards.

The CRPD strengthens the shift from institutional care by recognising the right of people with disabilities, including children, to live in the community, backed up with the necessary support and community-based

services to make that possible. It requires governments to make every effort to ensure that when a family cannot care for a child, the alternative placement is either with the wider family or in a family setting in the community.

Placing children in institutions involves removing them from public view and effectively rendering them invisible. It is an approach which identifies the child as a 'problem' to be got rid of. The philosophy underpinning the CRPD encourages the removal of the social, physical, cultural, attitudinal and economic barriers that impede the realisation of rights – not the removal of the child. In addition, investment must be made in recruiting, training and supporting foster families who can provide a home for children, or establishing small group homes where children can be cared for and participate fully within the local community when their own families are unable to care for them.

## No place like home<sup>62</sup>

In Romania, despite progress in closing down the worst of the large institutions, the quality of life for children who are unable to return home remains dismal. A home in the mountains containing 500 children was closed and 80 of the children were placed in a new home near Bucharest. When they arrived, most were unable to speak, were unable to feed themselves using cutlery, and lacked even the most basic knowledge of personal hygiene. This lack of skills bore no relationship to the potential capacities of the children concerned, but rather to the complete neglect of their care – a powerful illustration of the disabling impact of the institutional environment. They have now been taught these skills and some education is

provided. But it is a grim place to have to call home. It smells of urine, the children share all clothing, even underwear, and they have no privacy. The physical environment is sparse, with virtually no facilities for play. Hardly any of the children have contact with their families. The centre is run by a doctor and all the children are on daily medication to control their behaviour. Most of the children have rarely been outside the four walls of an institution in their entire lives. And the future facing them is even more bleak. Once they become adults, unless their families can take them home, they will transfer into long-term hospitals and stay there until they die.

## Evidence from around the world<sup>63</sup>

- Evidence that emerged from **eastern Europe** during the 1990s exposed the scale of neglect, amounting in some cases to torture and inhuman treatment, to which children with disabilities were subjected. In one girls' orphanage in **Moldova**, unfortunately not untypical, children were half-starved and neglected. Bedding was filthy and in 1996, 30 children died of cold and malnutrition. The orphanage director described them as imbeciles, although with care, education and support many would walk, talk and learn. There was money available but much of it was syphoned off by the staff. In a home in **Bulgaria**, 'mentally disabled' children were tethered to their beds and left to freeze at night when the heating was turned off to save money. In 1995, 15 children – one-quarter of the residents – died as a result. In the **Russian Federation**, orphanages are frequently filled with young children known as 'small-brained'. This can mean anything from children with cleft palates, hole-in-the-heart babies, or children with cerebral palsy or Down's Syndrome. They are often left to die as no one attempts to feed them. There is a lack of awareness that these children are educable living people. Rather, they are often referred to as imbeciles.
- In an asylum in **Iran**, children were tied to iron beds with thongs and chains in unnatural and painful positions. One 12-year-old lay virtually crucified on the concrete floor. His limbs were lacerated and infected where the manacles had bitten into his flesh, and cockroaches abounded.
- In **Greece**, to have a disabled child can be considered shaming and a cause of bad luck. The children are often placed in institutions. Typically, they may be tied to their beds, put in large, locked cots with bars over the top and force-fed on a diet of bread and milk while lying on their backs, and kept in these institutions throughout their lives.

### No forced separation from families

The UNCRC stresses that children should never be removed from their parents against their will, unless it is necessary for the best interests of the child, for example, where the parents are subjecting the child to abuse or are neglecting him or her. In addition, where removal is being considered, children themselves should be consulted and their views taken seriously, in accordance with their age and maturity.

The CRPD contains an additional key requirement that a child must never be separated from parents on the basis of disability. This means, for example, that doctors,

social workers, other professionals or the courts must never impose a decision to place a child away from parents simply because the child is disabled. Nor must they pressurise parents to agree to such a decision. The emphasis must be on providing for the child's needs within rather than away from the family. Both the UNCRC and the CRPD require that the best interests of the child must always be the paramount consideration. The forced institutionalisation of children with disabilities represents a form of discrimination. It would not be acceptable to deny the liberty of other children on this basis. Article 14 of the CRPD introduces a requirement on governments to ensure that people with disabilities, including

children, are entitled to enjoy the right to liberty on the same basis as others. It also requires that any deprivation of liberty must be neither unlawful or arbitrary and that the existence of a disability must never be used to justify the deprivation of liberty.

### **Prohibition on sterilisation**

In some countries, children with disabilities are sterilised in order to avoid the inconvenience of menstruation and unwanted pregnancy. It is sometimes even used as a form of 'child protection' to ensure that, given their disproportionate vulnerability to sexual abuse, they do not get pregnant if they are raped. Article 23(1)(c) of the CRPD emphasises the right of children with disabilities to retain their fertility. In other words, it is prohibited to sterilise them for any reasons other than clinical need. This will require changes in the law in many countries. In the USA, for example,

a number of states have legislation allowing the sterilisation of a child with a disability if there is a possibility that she might be unable to care for a child if she were to become pregnant.

### **Sterilisation of girls in Australia<sup>64</sup>**

In Australia, girls with learning disabilities as young as nine have been sterilised to prevent problems with pregnancy and to avoid the need to manage menstruation. According to a disability discrimination commissioner, 1,045 such sterilisations were carried out between 1992 and 1997.

### **Advocacy tips on the right to family life**

- **Review the legislation on detention and institutionalisation of children with disabilities. Advocate for changes that provide them with the same rights to family life as other children.**
- **Develop and provide training for professionals working with families on the rights of children with disabilities – eg, social workers, psychologists, teachers, doctors, early years professionals.**
- **Consult with parents and children on the support needed to ensure that the rights of children with disabilities are protected within families. Build alliances with parents' groups to advocate for more resources and services to meet these needs.**
- **Collect examples of breaches of children's rights to family life. Use these examples with the media, parliamentarians and policy-makers to raise awareness of the need for change.**
- **Promote models of good practice in foster care, community living and adoption. Work with the government to build a campaign to recruit foster carers for children with disabilities.**
- **Challenge violations of the right to family life through the courts.**
- **Gather evidence of the law and practice in respect of sterilisation of children with disabilities and campaign for changes in the law to prohibit the practice.**

## Right to social inclusion

### The key issues

Children with disabilities experience social exclusion in all arenas of their lives. Physical barriers are part of the problem, as well as lack of accessible public transport or public space, resulting in children with disabilities being unable to participate in the activities enjoyed by other children. These difficulties are compounded by the attitudinal barriers faced by children with disabilities. They are often shunned by their peers, marginalised from social and play activities, and physically and psychologically bullied. In consequence, it is common for children with disabilities to spend considerable parts of their childhood in isolation from all the usual activities associated with childhood.

## The rights

### UN Convention on the Rights of the Child

**Article 23** – rights of children with disabilities

### UN Convention on the Rights of Persons with Disabilities

**Article 3** – full and effective participation in society

**Article 8** – awareness-raising

**Article 9** – accessibility

**Article 20** – personal mobility

**Article 26** – habilitation and rehabilitation

## Life for children with disabilities in Montenegro<sup>65</sup>

Historically, the education and care of children with disabilities in Montenegro were based on a medical model taking disability as a deficiency, abnormality and a medical problem of an individual, caused by illness, trauma or some other medical cause. As a result, all interventions were aimed at the ‘correction’ of problems so that the children with disabilities could fit into the concept of ‘normality’ as much as possible. This widely accepted medical model resulted in entrusting the Commissions for Categorization with the decisions concerning the children’s education and care. In most cases, this brought about the segregation of children

with disabilities from the educational system, their families, their peers and society as a whole.

Prejudice about education for children with disabilities is very strong among professionals and in society in general. The huge stigma attached to disability means that disabled children are excluded from normal social contact and too often they are denied the chance to learn and play with other children. Families of disabled children are made to feel ashamed, and most often they hide the children in their homes, keeping them totally isolated.

Article 23 of the UNCRC establishes the right of children with disabilities to be able to enjoy a “full and decent life in conditions that ensure [their] dignity, promote self-reliance and facilitate the child’s active participation in society.” It also requires education, health, rehabilitation, recreation and employment services to be provided for children with disabilities to enable them to achieve the fullest possible social integration. The CRPD establishes as a general principle that children with disabilities are entitled to full and effective participation and inclusion in society. In order for this to happen, it is necessary to remove the many barriers that impede that participation.

### Removing cultural and social barriers

*“Well, in India, the major problem is that of awareness. Or rather, the lack of it... There’s also a kind of stigma associated with them, which is disgusting. There are laws that state that no school for ‘normal’ children can refuse admission to disabled ones, however, it is rarely followed; most schools do refuse admission to such children. All these factors lead to just one result: these children do not receive the education they deserve, the education that their peers receive.”*

(Girl, 17, India, quoted on UNICEF’s ‘Voices of Youth’ website)

*“Here in the USA the biggest problem is awareness, or, shall I say, lack of awareness of the children’s situation. A lot of people here consider disabled kids to be ‘weird, freaks,’ etc, and either ignore or mistreat them. Given, there*

*are special schools for disabled children, but sometimes such establishments only serve to isolate the children from mainstream society.”*

(Girl, 17, USA, quoted on UNICEF’s ‘Voices of Youth’ website)

The CRPD recognises that lack of understanding about the nature of disability, together with negative stereotypes and prejudices, serve to marginalise children with disabilities from active participation in society. Accordingly, it introduces detailed obligations on governments to take action to challenge those attitudes, and promote respect for, and positive images of, people with disabilities, including:

- public awareness campaigns to encourage receptiveness, and increase social awareness of the potential and abilities of people with disabilities
- fostering an attitude of respect for the rights of people with disabilities at all levels of the education system
- encouraging the media to promote positive images of people with disabilities
- developing awareness training programmes on the rights of people with disabilities.

Language plays an important role in reinforcing or challenging negative stereotypes of disability. People with disabilities have struggled for many years to challenge terms that are degrading and insulting. It is important that governments, the media and others in positions of power as well as individuals in their day-to-day relations are encouraged to use language that is acceptable to people with disabilities.

## Discriminatory and non-discriminatory language

<b>Outdated or offensive language</b>	<b>Reasons it is not acceptable</b>	<b>Currently accepted</b>
The disabled	Groups people into one undifferentiated category Condescending; does not reflect the individuality, equality or dignity of people with disabilities	People with disabilities
Handicapped	Implies that people with disabilities need charity Disabilities don't handicap: attitudes and architecture handicap	People with disabilities
Admits she/he has a disability	Disability is not something people 'admit' to or needs to be admitted to	Says she/he has a disability
Normal, healthy, whole	Implies that the person with a disability isn't normal	Non-disabled; person without a disability
Courageous	Implies the person has courage because of having a disability	Has overcome his/her disability; successful, productive
Deaf and dumb Dumb Deaf-mute	Implies mental incapacitation; simply because someone is deaf does not mean that they cannot speak	Deaf Non-verbal Hard of hearing Person who does not speak Unable to speak Uses synthetic speech
Confined to a wheelchair Wheelchair-bound	Wheelchairs don't confine; they make people mobile	Uses a wheelchair Wheelchair user Person who uses a wheelchair
Cripple Crippled	From Old English, meaning 'to creep'; was also used to mean 'inferior'; it is dehumanising	Has a disability Physical disability Physically disabled

*continued overleaf*

**Discriminatory and non-discriminatory language** *continued*

<b>Outdated or offensive language</b>	<b>Reasons it is not acceptable</b>	<b>Currently accepted</b>
Deformed	Connotes repulsiveness, oddness	Multiple disabilities
Freak Vegetable	Dehumanising	Severe disabilities
Crazy Insane Psycho Maniac Nut case	Stigmatising Reinforces negative stereotypes	Behaviour disorder Emotional disability Person with psychosocial disability
Retarded	Stigmatising	Developmentally delayed
Mentally defective Slow Simple Moron Idiot	Implies that a person cannot learn	Developmental disability Intellectual disability
Mongoloid	Considered offensive	Person with Down's Syndrome
Birth defect	Implies there was something wrong with the birth	Congenital disability
Midget	Outdated term; considered offensive	Person of short stature
Special needs	They are not special for the person – they are ordinary Term implies something that separates the child from others, but all children are different and need to be respected as such	Supported learning Additional learning needs

The media can play a critical role in challenging the barriers to inclusion:

- Respecting integrity – the media has a responsibility to avoid reinforcing negative or patronising stereotypes, and should never allow programming or articles that insult, denigrate or abuse children with disabilities.
- Raising visibility – many negative attitudes towards people with disabilities are sustained because these people are largely invisible throughout society. The media should make efforts to create opportunities for full participation in all forms of the media – employing disabled people (including children) as presenters, journalists, editors and commentators, and including characters with disabilities in soap operas, plays and comedies.
- Promoting access – much of the media is inaccessible to people with disabilities. The media should consult with representatives from organisations of people with disabilities, including children, on how to make the media more accessible through a wide range of communication forms and technologies.
- Challenging rights violations – the media has an important role to play in exposing rights violations, and challenging governments to fulfil their obligations under the CRPD.

### Removing physical barriers

The physical world is dominated by major barriers that inhibit the inclusion of children with disabilities from participation in an ‘ordinary’ life. The CRPD requires governments to identify and take measures to remove these barriers, and enable children with disabilities to access buildings, roads, transport and both indoor and outdoor facilities, including schools, housing, medical facilities and workplaces in both urban and rural areas.

To achieve these goals, governments must:

- develop and promote minimum standards and guidelines for ensuring the accessibility of facilities and services that are open to the public
- ensure that private entities providing facilities and services to the public take into account the need for them to be accessible to people with disabilities. This might include, for example, privately run bus companies, private schools, or care facilities
- provide training for all those who have a stake in accessibility issues – for example, administrators, architects, transport companies, and planners
- introduce universal design (see ‘Glossary’ for definition).

## Comments and questions made in the presence of children with disabilities<sup>66</sup>

- |                             |                                     |                                    |
|-----------------------------|-------------------------------------|------------------------------------|
| • Is he a Down’s Syndrome?  | • Is he dangerous?                  | • Such a pity!                     |
| • Is she spastic?           | • Is there a cure for it?           | • It’s so sad!                     |
| • Does she talk?            | • Have you tried for compensation?  | • His poor parents!                |
| • Is he yours?              | • Have you tried a dairy-free diet? | • Such a tragedy!                  |
| • Will he get better?       | • Can’t you keep her quiet?         | • Poor little thing!               |
| • Was she born like that?   | • What a shame!                     | • She should never have been born. |
| • Does she always do that?  |                                     |                                    |
| • Can’t you keep her still? |                                     |                                    |

## Overcoming the challenges<sup>67</sup>

*“In our city, there aren’t any conveniences for people with disabilities and every day I have to overcome many difficulties to move around, go to school and communicate with my friends. When I was seven months old, I got ill with poliomyelitis. Until I was five years old, I wasn’t even able to stand. After the surgery, with the help of a corset, orthosis and other support equipment, I got a chance to walk, and, thanks to the efforts of my mother, soon I was able to go to school together with my friends and peers. This year I entered the State Engineering University of Armenia and I want to receive a postgraduate education as well. Of course, the campuses of the university are not accessible for people who have difficulties; there are no elevators, there isn’t accessible public transport that I can use to get to the university. Despite these difficulties, I am going to my*

*lessons every day. Difficulties do not frighten me or my family.*

*“My grandmother was surprised to hear that in the university I was the only student who differs from others. Of course you can seldom see people like me walking in our streets and in public places. I would really like the Convention to force my country to be more attentive to people with different problems and to create equal opportunities for all. Aren’t we all the citizens of the same country? Don’t we have the same rights?”*

*“I am sure that we should tell our children more about the rights that the Convention provides, and tell the decision-makers about their duties.”*

*(Ashot Arsenyan, 17-year-old boy,  
Republic of Armenia)*

## Inaccessibility of the Internet<sup>68</sup>

The Internet can create opportunities for everyone; yet most of these opportunities are inaccessible to people with disabilities. In late 2006, some 100 leading websites in 20 countries were assessed against the international accessibility guidelines established by the World Wide Web Consortium (W3C). The websites surveyed included those focusing on travel, finance, media, government and retail shopping.

The survey found that most of the 100 websites examined did not meet international standards for accessibility; indeed, only three achieved

minimum accessibility standards. While some of the sites could be upgraded easily to accommodate people with disabilities, most need considerable work.

Making information technologies available to people with disabilities is not only a matter of human rights; it also makes good business sense. Studies suggest that accessible websites appear higher up the page rankings of search engines, can save costs on web maintenance, and provide the companies behind the websites with access to a largely untapped customer base.<sup>69</sup>

### Removing communication barriers

Much of the isolation and exclusion experienced by children with disabilities is a result of lack of accessible information, interpretation and assistance. Without this provision, many children with disabilities cannot communicate with or engage fully with the external world. Accordingly, the CRPD requires governments to ensure access, on an equal basis with others, to information, communications and other services, including electronic services and emergency services. It also requires the provision of:

- signs in Braille and in easy-to-understand formats in all public buildings and facilities
- forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters to help in access to buildings and other facilities open to the public.

### Removing mobility barriers

*“Township roads are narrow and have no pavement. Speed bumps have been built to prevent speeding but they did not consult with us and these bumps create a barrier for wheelchairs. Our rights have been violated as we have been excluded as road users.”*

*“Although a limited dial-a-ride service exists, it has to be booked in advance and is mostly used by older people. It means we have to organise our lives like a rota, whereas children without disabilities can act impulsively.”*

(Voices of children in South Africa<sup>70</sup>)

Lack of mobility forces many children with disabilities into isolation and dependency. They cannot participate in activities with their peers because they lack the facilities to get to those activities. The CRPD introduces obligations on governments to take measures to promote personal mobility and independence, including:

- providing facilities for personal mobility when and where children with disabilities need it and at affordable cost

- helping children with disabilities get access to quality mobility aids, devices and assistive technologies at affordable cost
- providing training in mobility skills both to children with disabilities and to staff working with them
- encouraging the production of mobility aids, devices and assistive technologies which take into account all aspects of mobility for children with disabilities.

### Building capacity for inclusion

Children with disabilities need support to enable them to achieve and maintain maximum independence and full participation and inclusion in all aspects of life. Lack of training, services and facilities contributes to social isolation and dependency. The UNCRC stresses that assistance must be designed to ensure that children with disabilities have effective access to education, training, healthcare services, rehabilitation services, preparation for employment and recreation opportunities. All these services should aim to ensure that they achieve the fullest possible social integration and individual development.

The CRPD introduces more specific obligations on governments to develop habilitation and rehabilitation services and programmes, particularly in the fields of health, education and social services, that are:

- provided at the earliest possible stage, multidisciplinary and based on individual needs and strengths
- provided as closely as possible to the communities in which children with disabilities live
- designed to support participation and inclusion in the community and in all aspects of society.

There is also a requirement to provide initial and continuing training for professionals and staff working in habilitation and rehabilitation and to promote the availability, knowledge and use of assistive devices and technologies relevant to habilitation and rehabilitation.

## Advocacy tips on the right to social inclusion

- **Work with children with disabilities to produce a film documenting and highlighting the multiple barriers that prevent their inclusion in ordinary life.**
- **Build support among journalists and programme editors to promote positive awareness of disability.**
- **Support the development of an advisory group of children with disabilities who can advise the government on issues of social inclusion and the removal of barriers.**
- **Take a group of parliamentarians together with key representatives from the media to a number of key public places to demonstrate the barriers they impose for children with disabilities.**
- **Campaign for a commitment from the government that it will always consult people with disabilities, including children, when implementing policies which affect social inclusion, eg, the design of new coins, buildings, transport, etc.**
- **Lobby the government to work towards universal design.**

## Right to education

### The key issues

*“... interaction with others is the greatest learning tool and children of all abilities interacting with one another is mutually beneficial – regardless of ability, they all need a helping hand to learn.”*

(Girl, 20, Australia, from UNICEF’s ‘Voices of Youth’ website)

The challenges faced by children with disabilities in realising their right to education are profound:

- **Lack of access** – it is estimated that as many as 90% of children with disabilities in the developing world receive no formal education. The commitments made under Education for All and the Millennium Development Goal of universal access to primary education by 2015 are unlikely to be achieved for many of the world’s children with disabilities.
- **Lack of identification and assessment** – many children do not receive early

identification and assessment of their needs and therefore fail to obtain the support and help they need. Children are thereby denied the opportunity to achieve their potential.

- **Lower quality** – even where children with disabilities do have access to education, for many children it is of a lower quality, following a different curriculum, in segregated settings, and rarely beyond primary level.
- **Segregation** – many children with disabilities are sent to segregated special schools, including in many cases residential schools where they spend most of their childhoods. This system deprives them of family life and involvement in their local community, and restricts them to an institutionalised life shut away from the external world.
- **Discrimination** – of the minority who do gain access to school, significant numbers drop out in the face of discrimination, lack of appropriate resources and appropriately qualified teachers, and bullying from peers.

In its General Comment on the aims of education, the Committee on the Rights of the Child observes that discrimination is pervasive in both many formal and informal education systems.<sup>71</sup> Yet, without access to education, children with disabilities are denied opportunities to develop their potential, have little chance of employment in the longer term and are condemned to remain trapped in poverty for the rest of their lives. Not surprisingly, challenging this bleak picture has been a high priority for the disability movement. Education is the primary route through which to challenge the entrenched social exclusion, poverty, marginalisation and stigma faced by children with disabilities in so many countries throughout the world.

## The rights

### **UN Convention on the Rights of the Child**

**Article 28** – child’s right to education

**Article 29** – the aims of education

**Article 23** – rights of children with disabilities

### **UN Convention on the Rights of Persons with Disabilities**

**Article 24** – right to inclusive education

## Getting an education in Serbia<sup>72</sup>

Primary and secondary education of children with disabilities in Serbia today is conducted in: 1) special schools for children with disabilities, 2) special classes for students with disabilities in mainstream schools, and 3) mainstream education classes where students with disabilities are educated together with their non-disabled peers.

1. In the 2002/03 school year, there were 8,829 students with disabilities educated in 85 special schools in Serbia, but only 1,269 of them were in secondary education. Most special schools educate students classified as ‘mentally retarded’, and instruction is conducted by ‘defectologists’, teachers educated for work with children with disabilities, whose professional training is primarily based on the medical model.

2. There were 70 mainstream education facilities with special classes educating 1,374 children with disabilities. Again, their education was provided by 155 ‘defectologists’ and 97 teachers with other formal professional training.

3. There is no data about the number of children with disabilities included in mainstream education classes, but some sources roughly estimate that it does not exceed 15%.

Very few children with disabilities are included in preschool education. The UNICEF analysis of the overall educational system points to an alarming situation where only 1% of all preschool age children with disabilities are included in the public educational system, as against 27% of all children in Serbia.

## Early childhood education

Access to early childhood education is of value for all children, but is of particular significance for children with disabilities, many of whom need additional support to compensate for the barriers they face as a consequence of their impairment. For example, whereas hearing children are exposed to language from birth, deaf children are not and will need help in acquiring skills in communication and opportunities to catch up on the learning they inevitably miss out on. By the time they reach primary school age, they will already be disadvantaged if they have not had access to early education.

Neither the UNCRC or the CRPD make explicit reference to early childhood education. However, the Committee on the Rights of the Child, in its General Comment on early childhood, states that it interprets the right to education during early years as beginning at birth, and closely linked to the child's right to maximum development, as elaborated in Articles 6 and 29 of the UNCRC.<sup>73</sup> And in the General Comment on children with disabilities, it emphasises the particular importance of early childhood education as the means by which early identification and assessment can be undertaken and responded to. In other

words, a holistic interpretation of the UNCRC, consistent with a commitment to promoting the best interests of children with disabilities and to non-discrimination, would require governments to invest in quality early years provision for all children, including children with disabilities. Such provision needs to be inclusive and designed to respond flexibly to the individual needs of children.

## Access to education

*“Unless and until these children receive an equal education, they cannot be independent and self-reliant.”*

(Girl, 17, India, from UNICEF's 'Voices of Youth' website)

The UNCRC affirms the right to education for every child. It also stresses that it must be provided on the basis of equality of opportunity. To this end, governments must ensure that children with disabilities receive an education on the same basis as other children. This means that they have the right to free and compulsory primary education, to secondary education, which is free wherever possible, and to higher education on the basis of capacity. Children with disabilities must get help and information to enable them to make informed vocational and career choices.

## Gender further disadvantages blind girls<sup>74</sup>

In India, blind girls have suffered particular discrimination in relation to education. For example, in New Dehli, during the 1990s, of the ten schools for blind children, only one was for girls and one was co-educational. Only 10% of blind children in Asia have access to education, and a very large proportion of blind girls are illiterate. Efforts to promote the rights of girl children to education have still not reached blind girls.

## Uganda – promoting access to education for children with disabilities<sup>75</sup>

Uganda has guaranteed free primary education for up to four children in every family, with priority given to children with disabilities. As a result, the number of children enrolled in primary schools has risen from 2.5 million in 1996 to 7.6 million in 2003, while the number of teachers increased from 38,000 in 1980 to over 90,000 in 1998.

The CRPD elaborates these rights in more detail. Firstly, it reaffirms the absolute right of children with disabilities to education without discrimination and on the basis of equality of opportunity. It also requires that governments take note of the following:

- Disability must never be a basis for excluding a child from primary or secondary education. The current practice in some countries, for example, of categorising some groups of children as ‘uneducable’ is prohibited.

- Children with disabilities must be able to access inclusive, quality primary and secondary education on an equal basis with others in the communities where they live. This provision requires that children with disabilities are able to go to their local schools in the same way that other children do.

In order to ensure that this right is fully implemented, it is imperative that responsibility for the education of children with disabilities

## Schools must adapt to children, not expect all children to adapt to the school<sup>76</sup>

*“When I was nine years old, I had a brain tumour removed and afterwards I had problems with my eyes. Before the operation, I was one of the clever kids in a normal school. My teacher let me return to the school and I was completely accepted. I had no difficulties. However, at secondary school, there was a teacher who wouldn’t help me. He wouldn’t*

*let my friend read what was on the blackboard for me. He threw me out of the class and told me to go to hospital where I belonged. I was then sent to a special school. I felt I was like any other child – it was the maths teacher who needed educating. Teachers need to learn to be flexible in their methods.”*

lies with the Ministry of Education, on the same basis and with the same rights as all other children. It must not remain, as too often happens, with ministries of social welfare.

The barriers to education for children with disabilities exist at a number of levels, all of which must be addressed if the right to education is to be achieved. The CRPD introduces specific obligations to ensure that these provisions are implemented, and that children with disabilities get access to education. These obligations are:

- early identification and assessment of children
- legislation that affirms the right of children with disabilities to education on an equal basis with others
- schools to make ‘reasonable accommodation’ (see ‘Glossary’ for definition) so that schools are physically accessible for all children
- provision of accessible transport to school
- provision of the necessary aids and adaptations to enable all children to learn on an equal basis

- flexibility in the curriculum and the teaching methods
- awareness-raising of teachers, parents, religious and community leaders to enhance understanding of disability and the rights of children
- provision of effective individualised support measures to maximise children’s academic and social development, including:
  - enabling children to learn Braille, alternative script, augmentative and alternative modes, means and formats of communication, orientation and mobility skills
  - enabling children with hearing impairments to learn sign language and promote the linguistic identity of the deaf community
  - ensuring that the education of blind, deaf and deafblind children is delivered in the most appropriate language and means of communication
- training and employment of teachers qualified to work in inclusive environments, and, where necessary, in sign language and/or Braille.

## The value of teacher training<sup>77</sup>

In a remote community in Mongolia, there are 30 children with disabilities who should attend school. Three of them are unable to attend school at all. Their disabilities are very severe and they live in particularly isolated parts of the countryside. The local teacher was trained by Save the Children to work with children with disabilities, and following the training she has worked closely with the children with disabilities. She was very keen to reach the children unable to get to school, and with the support of the doctor and APDC (Association

of Parents of Disabled Children) went to their homes to work with the families. Over time, she has developed a distance learning package and now those children come to the school occasionally, but their parents come for training and support and then teach their children at home. This teacher has developed materials and a package for home learning. The school said that they selected this teacher for the training as she is so dedicated and they knew she would really make the most of it – and she proved them right!

## A failure to adapt<sup>78</sup>

In one school in El Salvador, the 7th grade class was held on the upstairs floor. A child using a wheelchair was moving into that class and asked for the room to be changed to the ground floor. He was told that the 7th grade was always taught in that room and it was impossible to change it. Accordingly, he had to be lifted up at the beginning of the day and down again at the end. As the toilets were on the ground floor, he was unable to use them throughout the day.

### Inclusive quality education

*“I got higher exam results than all the students in the same year group as me who were in the special school; and not because I’m cleverer, but just because of the opportunities I’ve had and the opportunities I’ve been given.”*

(Blind student from the UK speaking to the UN Ad Hoc Committee in New York)

*“Care providers cannot understand that we are all different, even if we have the same condition. What we want to say to all adults who take care of us is that we are 48 different personalities. There is no personality type known as muscular dystrophy.”<sup>79</sup>*

(Statement from a group of 48 children with muscular dystrophy in France)

It is not sufficient that children with disabilities have access to education. *It must also be inclusive.* The UN made a clear commitment to promoting inclusive education as early as 1994 in the Salamanca Statement, which called on governments to “adopt as a matter of law or policy the principle of inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing

otherwise”.<sup>80</sup> UNESCO, as the lead UN agency on education, provides the following definition of inclusion: “Inclusion is seen as a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the regular system to educate all children... Inclusion is concerned with the identification and removal of barriers...”<sup>81</sup>

The UNCRC does not specifically demand inclusive education, although, as noted above, it does insist on the right to an education on the basis of equality of opportunity and on education designed to achieve the child’s fullest possible social integration. The Committee on the Rights of the Child, however, stresses that inclusive education should be the goal of educating children with disabilities, and it encourages all governments to begin a programme that aims to achieve inclusive education.

## “But isn’t ‘special education’ better for children with ‘special needs?’”<sup>82</sup>

Research in the UK confirms that many of the arguments put forward to defend the practice of ‘special’ education cannot be defended.

- **Special schools are better equipped and resourced** – but despite higher allowances per student they have lower total budgets and lack the capacity to offer the range of facilities that mainstream schools have, such as libraries and technology, drama and sports departments. Many of the high costs of special schools – eg, for transport, boarding costs, selection procedures, do not necessarily benefit the children who would be better transferred to mainstream schools.
- **Special schools have higher staff ratios** – but often not to the benefit of students,

who were observed to spend much time waiting for lessons or repeating simple tasks. The staff in special schools often lack the subject specialisms available in mainstream schools.

- **Special schools protect from educational failure and bullying** – but protection from failure is often at the expense of offering opportunity. And bullying is evident in special as well as mainstream schools. Promoting inclusive cultures in all mainstream/ordinary schools is surely a better way of tackling the problem than separating children.

The CRPD goes further and insists on an inclusive education system at all levels. It is important to stress that simply placing excluded children within a mainstream setting does not of itself achieve inclusion. This can only be achieved by addressing all aspects of the education system, including the curriculum, teaching methods, school culture and the school environment. All levels of the system must be adapted to ensure that the system adapts to the child, rather than expecting the child to adapt to the system.<sup>83</sup>

At **national** level, this requires governments to ensure that sector plans and implementation frameworks:

- are produced through consultation with disabled people’s organisations, parents of children with disabilities and children’s organisations
- adapt teacher-training syllabuses to include inclusive education methodologies

- encourage and support people with disabilities to train as teachers
- require schools, language of instruction and learning materials to be accessible for all children, including those with disabilities
- promote peer-education programmes in which older students support younger students
- involve parents actively in their children’s education and enlist their support to strengthen the contribution of the school to children’s education
- turn existing special schools into resource centres
- introduce mechanisms to ensure that data is collected on enrolment, attendance, completion and attainment of children with disabilities
- build links between community-based rehabilitation and education services.<sup>84</sup>

*“Inclusive education has not only benefited the children with disabilities but also benefits all the other non-disabled students in the school by teaching them how to care about others and help others.”*

(Headmaster from Xin Dian Primary School in Sanshitou, China)

*“It is the first time for me to understand in depth the idea of inclusive education, after I participated in several training workshops. I started to pay more attention to those children with special education needs and respect children’s diversity.”*

(A key teacher from an inclusive education pilot primary school, Anhui, China<sup>85</sup>)

In addition to action taken by governments at national level, there is also a great deal that **schools** themselves can do to create inclusive cultures, policies and practices. For example:

- **Promoting a respectful inclusive environment:** Schools have a key role to play in translating policies of inclusion into the day-to-day life of the school. All children need to feel welcome and confident of equal treatment within the school. Schools need to promote an atmosphere of respect for all children, and instigate a culture that ensures no bias is tolerated which favours or discriminates against any learner or group of learners, whether in respect of admission procedures, treatment within the classroom,

## Promoting an inclusive environment<sup>86</sup>

Save the Children runs an Inclusive Education Project in Egypt which aims to ensure that disabled children have access to education and that the quality of education for all children is improved. It does this through training teachers and other educational personnel, the presence of in-school support teams, mobilising community support and advocating for changes to education at the national level.

Parents of disabled children included in project schools consistently reported that their children were learning more than before (when they were at home, at a special school or, in one case, at a non-inclusive school). They and teachers noticed particular improvement in the children’s social, communication and behavioural development. This was also borne out during observations of and interviews with disabled children. Academic learning was very good in some children; in Minya, a hearing-impaired girl came top of her class. Disabled children and their parents reported that the children loved going to school; one child even

rang the teacher in the holiday to say how much he missed her.

Teaching in Egypt is generally based on chalk-and-talk methods, with children being passive recipients of information. Teachers trained by the project and those who know their work said that teachers used more educational materials, varied their teaching techniques and were more patient with the children (several teachers specifically said that they hit children less). Non-disabled children have also participated in the activities organised by the project, which they enjoyed very much. Sixty per cent of teachers interviewed said they had seen grades, learning and behaviour in their classes improve as a result of the changes they had made after the training.

*“We are no longer just a tool, we have become a teacher. We no longer teach a class, we are teaching 40 individual children.”*

(Teacher, Alexandria)

## Advocacy to promote inclusive education<sup>87</sup>

Save the Children has worked with key stakeholders in Montenegro to promote inclusive education. This has involved working with children, their parents and professionals in institutions, as well as direct lobbying of top policy-makers within government. This advocacy bore fruit in 2004 when Parliament adopted the new law on education of children with special needs, which recommends inclusion of children with disabilities in mainstream classrooms, whenever it is possible to achieve this. The Ministry of Education has also accepted inclusive education within its strategic decisions and documents, making inclusion of disabled children in preschools, schools and teachers' training an integral part of practice in all schools.

The National Action Plan for Children, 2004, states: "Montenegro has committed itself to improving the approach to the high-quality education for all boys and girls, from the infant nursery to the secondary school, and to enabling everyone equal access to the education system, with special focus on the children from national minority and ethnic groups and children with special needs. It is expected that the number of special needs children will have increased by 2010, specifically by 5% a year in the preschools and by 25% a year in the inclusive classes." Additionally, from 2005, the Ministry of Education decided to introduce the subject of inclusive education in the Faculty of Philosophy and departments for the education of preschool and school teachers and other educators.

opportunities for learning, access to examinations, opportunities to participate in particular activities, such as music or drama, or marking of work. Children should never be stereotyped or insulted on the basis of who or what they are. Schools need to develop policies setting out the principles of non-discrimination and ensure that all teachers, parents and children are aware of the policy and know how to make a complaint if it is breached. Children and parents should be involved in the development of the policy, as this will strengthen ownership and understanding. The process of developing the policy is also an opportunity to address the issues and learn why they are important, and to develop skills in negotiation, listening, and understanding different points of view and types of experience.

- **Accommodating differing needs:** Inclusion necessitates action to accommodate differing needs of children. Schools can pilot models of education which, for example, allow more flexible participation in the classroom or different hours of teaching.
- **Engaging children as partners:** Schools need to promote environments in which the skills and energies of children are enlisted to provide support for other children. Older children can serve as mentors to younger children. Sighted children can be paired with blind children to work collaboratively. Deaf children can help teach hearing children to sign. Children with different disabilities can provide expertise on the barriers that exist in a school and how to remove them.

## The economic and moral case for inclusive education for all children with disabilities

Given the scale of the difficulties faced by many governments in developing countries in achieving the Millennium Development Goal (MDG) of universal access to primary education, it is all too easy for the rights of children with disabilities to be sidelined and afforded low priority. However, there are powerful economic, as well as moral, arguments for making inclusive education for all as a matter of priority.

- Unless the rights and needs of children with disabilities are incorporated into the development of education at the earliest stages, the education system will become entrenched in an ‘able-bodied’ culture and ethos, which will subsequently be far harder to change: buildings will be designed without disabled access, teachers will not be appropriately trained and equipment will fail to take account of the needs of children with disabilities. Governments that are working towards the attainment of the international development target of universal access to basic education by 2015 must commit themselves now to ensuring that equal opportunities for all children inform their strategies for achieving that goal.
  - A World Bank report has suggested that universal primary education cannot be achieved in developing countries without the inclusion of children with disabilities in mainstream systems, and that they can be successfully and much less expensively accommodated in inclusive rather than segregated settings. Furthermore, educational benefits for all children may be associated with quality improvements
- which are inherent in providing inclusive primary education, through major changes in the way schooling is planned, implemented and evaluated. The report also argues: “If segregated special education is to be provided for all children with special educational needs, the cost will be enormous and prohibitive for all developing countries. If integrated in-class provision with a support teacher system is envisaged for the vast majority of children with special educational needs, then the additional costs can be marginal, if not negligible.”<sup>88</sup>
- It is a fundamental principle of both the UNCRC and the CRPD that all the rights they embody extend to all children without discrimination. Any policy that directly or indirectly excludes children with disabilities from accessing rights undermines its very ethos. It will feed into and affirm existing prejudices that children with disabilities are less worthy or valued than others and it is inimical to a commitment to respect for human rights.
  - One of the messages emerging from the General Discussion Day on the rights of children with disabilities, held by the Committee on the Rights of the Child in October 1997, was the importance of recognising children with disabilities as contributors to society, not burdens. It is in the economic interests of the government to invest in the education of children with disabilities in order that they can become effective members of the labour force as they grow up.

## **Achieving inclusive education<sup>89</sup>**

### **Principles**

- Every child has an inherent right to education on the basis of equality of opportunity.
- No child is excluded from, or discriminated within, education on grounds of race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth, poverty or other status.
- Respect is afforded to the ability of all children to learn and benefit from education.
- Schools adapt to the needs of children, rather than children adapting to the needs of the school.
- Children's views are listened to and taken seriously.
- Individual differences between children are a source of richness and diversity, and not a challenge.
- The diversity of needs and patterns of development of children are addressed through a wide and flexible range of responses.

### **Practice**

- Understand inclusion as a continuing process, not a one-off event.
- Strengthen and sustain the participation of children, teachers, parents and community members in the work of the school.
- Restructure the cultures, policies and practices in schools to respond to the diversity of pupils within their locality. In other words, focus on identifying and then reducing the barriers to learning, rather than concentrating on what is 'special' about the individual child and targeting services to address the 'problem'.
- Provide an accessible curriculum, appropriate training programmes for teachers, and, for all students, fully accessible information, environments and support.
- Identify and provide support for teachers as well as students.

## Advocacy tips on the right to education

- Advocate for the introduction of legislation to ensure the equal right of every child to an education without discrimination of any form, on any grounds.
- Advocate for an end to segregated ‘special’ education and for the right of all children to a properly supported inclusive education in the general system.
- Press the government to provide accurate data on the numbers of children with disabilities in and out of school.
- Advocate for strategies to achieve the Education for All goals and MDGs to make explicit provisions to realise the right of children with disabilities to education.
- Develop and promote models of good practice in inclusion and participation – how it can be done, what resources and facilities are needed, the impact on children and the educational outcomes.
- Develop and provide training resources for teachers on working in inclusive environments. Advocate for this training to be incorporated into pre- and in-service training for all teachers.
- Support groups of children with disabilities to become advocates for the right to education. Promote opportunities for them to speak to community groups, school governing bodies, media and government representatives.

## Right to participate in play, cultural life, recreation, leisure and sport

### The key issues

*“As neighbours realised that my child was different and that a disability was becoming visible, they prevented their children from visiting my home, as they were scared that their children would bring bad luck home.”*

(Parent in Romania<sup>90</sup>)

*“My family said I was useless. I was never allowed to join in with other members of the family.”*

(Child in Romania<sup>91</sup>)

It is probably in the field of play, recreation and leisure activities that children with disabilities

experience the most acute sense of social exclusion and marginalisation. Consultations with children repeatedly reveal the importance that they all attach to their relationships with their peers. Children with disabilities are no different. They, too, want opportunities to be with friends, to play, to have fun, to ‘hang out’. However, for them, physical, attitudinal, cultural and social factors can place almost insuperable barriers in the way of the daily activities that other children are able to take for granted. Play is also at the core of children’s physical, cognitive, social, moral and emotional development. It is invaluable for exercising creativity, as protection for working children, as a therapeutic tool and as a means of celebrating cultures and communities. Accordingly, exclusion from play represents a major exclusion from life for children with disabilities.

## The rights

### UN Convention on the Rights of the Child

**Article 31** – child’s right to leisure, play and culture

**Article 15** – child’s right to freedom of association and peaceful assembly

**Article 17** – child’s access to appropriate information

### UN Convention on the Rights of Persons with Disabilities

**Article 30** – participation in cultural life, recreation, leisure and sport

equal opportunities, taken in conjunction with Article 2, the right to non-discrimination, clearly states that provision must be encouraged for every child, including children with disabilities.

- **Play appropriate to the age of the child** – the Committee on the Rights of the Child interprets this provision as including the mental and psychological capabilities of the child as well as his or her chronological age. This means that the importance of opportunities for play which is appropriate for children with different aptitudes, capacities and interests must be recognised.
- **Inclusive play** – the Committee on the Rights of the Child has emphasised that opportunities for children with disabilities to play with and alongside non-disabled children is a vital building block towards developing an inclusive society.

## Play, recreation, and leisure

Article 31 of the UNCRC highlights three dimensions of the right to play that need to be addressed in respect of children with disabilities:

- **Opportunity for play and recreation** – it recognises the right to play, leisure and recreation, and also requires governments to encourage the provision of appropriate and equal opportunities for recreational and leisure activity. The specific reference to

The CRPD builds on the UNCRC. It imposes a specific obligation on governments to take appropriate measures to ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure, including those activities within the school system. This obligation must not be understood as being limited to the provision of parallel opportunities that are equal but separate. Rather, it clearly implies the right to equal and inclusive opportunities for play.

## The loneliness of exclusion from play<sup>92</sup>

Saaid is a ten-year-old boy from Marrakesh. He has a muscular condition that weakens his arms and legs and limits his mobility. He wants to play with other children but they will not play with him, saying that he will hurt himself. He is not even allowed to do ordinary activities in the

house that he knows he can do. As a result, he feels excluded from the things that his peers enjoy doing. Even if he is clumsy and cannot do things ‘properly’, he believes he should be allowed to try in order to gain confidence and encourage others to accept him for who he is.

## Sport

Although the UNCRC does not mention sport, the UNCRC, in its General Comment on children with disabilities argues that they should be provided with equal opportunities to participate in sports which, it argues, are a medium for realising a satisfying quality of life. It states that there should be opportunities, wherever possible, to include children with disabilities in sporting activities together with other children. However, it also recognises that there will be some sporting activities where children with disabilities need separate opportunities where they can compete safely. It encourages the media to give as much attention to the activities of children with disabilities as to those of other children.

The CRPD is consistent with this approach and introduces an obligation to promote participation of children with disabilities in

mainstream sporting activities at all levels, as well as ensuring there are opportunities for them to organise, develop and participate in disability-specific activities. In order to achieve this goal, governments must encourage the provision of appropriate instruction, training and resources on an equal basis with others.

## Cultural life

Article 31 of the UNCRC not only recognises the right of children to participate freely in cultural life and the arts, but goes on to stress that governments must respect and promote this right, and encourage appropriate provision and equal opportunities for cultural and artistic activity. In addition, Article 17 requires governments to encourage the mass media to disseminate information and material of cultural benefit. The Committee on the Rights of the Child has emphasised that children with disabilities must be provided

## The value of sport<sup>93</sup>

The Special Olympics stands as a leader in the field of intellectual disability. It is a truly global movement, with more than 500,000 athletes in China, more than 210,000 in India, almost 550,000 in the USA, more than 600 in Afghanistan and 4,400 in Rwanda. Special Olympics World Games were held in Ireland in 2003 and Japan in 2005 and, in 2007, China hosted the World Summer Games. Most importantly, Special Olympics sharpened the focus on its mission as not just 'nice', but critical, not just as a sports organisation for people with intellectual disabilities, but also as an effective catalyst for social change.

Children and adults with intellectual disabilities who participate in Special Olympics develop improved physical fitness and motor skills, greater self-confidence and a more positive self-image. They grow mentally, socially and spiritually and, through their activities, exhibit boundless courage and enthusiasm, enjoy the rewards of friendship and ultimately discover not only new abilities and talents but their 'voices' as well.

with equal opportunities to participate in such activities.

The CRPD recognises the multiple barriers that impede access to cultural and artistic life for children with disabilities. It therefore introduces very clear obligations which, if implemented, would serve to remove those barriers, as follows:

- Cultural materials, including novels, poetry, plays and magazines must be made available in accessible formats.
- Cultural activities such as television programmes, theatre, concerts and films must be available in accessible formats.
- Cultural performances or services such as theatres, museums, cinemas, tourism services and libraries must be accessible and, as far as possible, access to monuments and sites of national cultural importance must be made available.

In addition, it requires that governments take appropriate measures to enable children

with disabilities to have the opportunity to develop and utilise their creative, artistic and intellectual potential. Too often, their social exclusion means these children are denied these opportunities. This provision will necessitate action on the part of governments to ensure that children with disabilities have access, on an equal basis with others, to both mainstream and specialist education in the fields of music, art, drama, photography and dance. Encouragement should be given to the media to ensure that the artistic work of children with disabilities is afforded equal recognition. The CRPD acknowledges that the opportunities for participation in the arts will not only benefit children with disabilities themselves, but will also enrich society.

Finally, the CRPD stresses that there must be, on an equal basis with others, recognition of and support for the specific cultural and linguistic identity of children with disabilities, such as sign languages and deaf culture.

### **Advocacy tips on the right to participate in play, cultural life, recreation, leisure and sport**

- **Undertake a review of the visibility, participation and treatment of children with disabilities in the media including print, radio and television media. Use the findings to highlight the need for change.**
- **Work with a group of children with disabilities to evaluate the accessibility of local play facilities. Publicise the results and promote ideas from the children about what is needed in order for them to use these facilities.**
- **Lobby the government to introduce regulations requiring all public sports facilities to promote access for children with disabilities.**

## Right to the best possible health

### The key issues

Of the approximately 150 million children with disabilities, few in developing countries have effective access to health and rehabilitation or support services. Mortality for under-fives can be as high as 80% in some countries.<sup>94</sup> Many children with disabilities find that healthcare facilities, including dentists' and doctors' surgeries, and clinics, are physically inaccessible to them, and that health professionals do not understand their condition and cannot communicate with them, or they treat them with indifference or contempt. These children are often unable to reach healthcare facilities, owing to lack of accessible transport. Services to address their specific needs are also often lacking. In consequence, they experience inadequate healthcare, and certainly a lower quality of service than non-disabled children.

There is still a widely held view in many countries that adolescents with disabilities cannot or should not be sexually active. They are therefore often denied the right to form sexual relationships, and access to the information and services that they need in order to make safe and informed choices within those relationships. Children with disabilities experience widespread disregard for their views when decisions related to their healthcare are being made. They are often over-protected by their parents, who underestimate their capacities and make decisions on their behalf. Similarly, health professionals often fail to involve children with disabilities, not providing them with information and opportunities to ask questions, and displaying a lack of interest in or respect for their views. Yet, in practice, many children with disabilities, who may have significantly more experience of medical interventions than other children of comparable ages, are likely to have greater understanding of their condition, and to have acquired greater capacity for informed decision-making.

## The rights

### UN Convention on the Rights of the Child

**Article 6** – child's right to life and maximum survival and development

**Article 24** – child's right to health and health services

### UN Convention on the Rights of Persons with Disabilities

**Article 10** – right to life

**Article 25** – health

The right of every child to optimum development and to the best possible health, without discrimination, is explicitly established in the UNCRC. It is reaffirmed in the CRPD. The UNCRC also introduces a number of specific obligations on the part of governments to ensure the realisation of the right to the best possible health. The CRPD complements the UNCRC with additional provisions which address the particular difficulties faced by children with disabilities in achieving access to healthcare.

### Equality of access

The CRPD places an obligation on governments to ensure not only that children with disabilities can access health services, but also that they are provided with the same range, quality and standard of healthcare and health programmes as others. It also requires health professionals to provide the same quality of care. This means that action must be taken to ensure that all health facilities and equipment are accessible. In addition, health professionals will need training in the treatment of children with different disabilities, and interpreting should be provided where necessary.

## **Participation, information, informed consent and evolving capacities**

The UNCRC stresses that all children, including children with disabilities, who are capable of forming a view, have the right to express their views freely on all matters of concern to them and to have their views given due weight in accordance with their age and maturity. In addition, parents or others legally responsible for them must have regard to children's evolving capacities when providing direction and guidance. In respect of health, this means that children are entitled to be involved in decisions concerning their healthcare and treatment. In other words, children with disabilities must be listened to, respected and involved in decision-making on exactly the same basis as all other children.<sup>95</sup> These principles are reinforced in the CRPD, and must be respected by all health professionals.

In order to implement these rights, children with disabilities must be:

- provided with age-appropriate and accessible information, in formats appropriate to their needs, and given the time and space to explore their views
- encouraged to communicate in whatever mode is appropriate for them. For example, younger children, or children with intellectual impairments, may find it easier to communicate through non-verbal forms of communication such as play or drawing
- enabled to take responsibility for those decisions they are competent to make.

Health professionals need to be provided with training to raise their awareness of these rights and to help them involve children in decision-making.

## **Provision of specific services**

Children with disabilities may require some health services specifically because of their disabilities. They need, for example, early identification and intervention to ensure that any impairments are diagnosed at the earliest possible stage and that appropriate services are provided. Article 25(b) of the CRPD places an obligation on governments to ensure that the specific health services required by children with disabilities are provided. Paragraph (c) also requires that these services be located as closely as possible to children's own communities. Local services are of particular importance to children with disabilities, because of both poverty and the practical difficulties they face in accessing transport. These provisions are consistent with the obligation in both Conventions to ensure that children with disabilities achieve the highest possible standard of health, and with Article 6 of the UNCRC, which stipulates that governments must ensure the development of the child to the maximum extent possible.

It is important to involve children with disabilities, as well as their families, when developing health policies and in planning both the nature of the services needed and their location and design. The right to express views, embodied in the UNCRC, applies not only to children as individuals, but also to matters affecting children as a whole. Article 4 of the CRPD includes an explicit obligation to consult representative organisations of children with disabilities when developing policies affecting them. These children will have a considerable body of expertise on their own needs, the barriers they face and how to overcome them. Children with disabilities can also be involved in research to explore the effectiveness of healthcare services, and in evaluating and monitoring health care.<sup>96</sup>

## A gap between paper rights and actual rights<sup>97</sup>

A group of children in Romania acted out a role play to illustrate the gulf between their 'paper' rights and their actual rights. The role play consisted of a family visiting the doctor, who recommended a course of physiotherapy for a child for two hours a week for a year. The cost would be \$60 a month. The father, a policeman, earned only \$100 a month and his rent was \$60. It was impossible to find the money, so the doctor refused to arrange the treatment. All healthcare for children is supposed to be free. But many doctors demand payment before offering services. It is widely acknowledged that many health professionals – doctors, physiotherapists, nurses – demand these 'backhanders', but little action is taken to address it.

### Sexual and reproductive health

The UNCRC includes an obligation to provide family planning education and services. The General Comment on adolescent health and development produced by the Committee on the Rights of the Child elaborates this right, arguing that to be consistent with the best interests of young people and their right to information and to family planning education, young people should be provided with access to sexual and reproductive information, including information on family planning and contraception, the dangers of early pregnancy, the prevention of HIV and AIDs and the prevention and treatment of sexually transmitted diseases (STDs).<sup>98</sup> This should be provided regardless of their marital status or whether their parents consent. Services for the prevention and treatment of STDs and HIV and AIDs should also be provided, including measures to remove all barriers hindering access to preventive measures, such as condoms. These measures must apply equally to adolescents with disabilities.

The CRPD introduces additional measures to ensure that there is no discrimination against people with disabilities in respect of relationships, which they are entitled to form on exactly the same basis as others. It also emphasises that they are entitled to the same sexual and reproductive health programmes as others. In order to ensure that they have equal access, it will be necessary to make materials available in Braille, and through other new information and communication technologies and systems. Such programmes must be provided in the languages and modes and means of communication that are the most appropriate for the adolescents involved. Where peer education is being used as the means of providing health education, consideration should be given to involving adolescents with disabilities as peer educators.

### Prevention of disability

The CRPD requires governments to introduce services designed to minimise and prevent further disabilities, including among children,

although it does not specify the nature of those services. However, the UNCRC, although it does not make an explicit link with disability prevention, does introduce a range of obligations that are of direct relevance. These include combating disease and malnutrition through access to an adequate diet and clean drinking water, measures to address environmental pollution, hygiene and

environmental sanitation, parental education, support for breastfeeding and prevention of accidents. These obligations, if implemented fully by governments, would significantly lessen the risk of disability. It is important therefore to use the provisions of the two Conventions together when advocating for the necessary preventive measures to reduce the risk of disability.

### **Advocacy tips on the right to best possible health**

- **Conduct research into the experiences of children with disabilities in healthcare services. Use the findings to advocate for the necessary changes to protect their right to the best possible healthcare.**
- **Advocate for early identification and referrals.**
- **Support a group of children with disabilities to undertake an audit of local hospitals, doctors' surgeries and health centres in order to assess how disability-friendly they are.**
- **Undertake a survey of reproductive health services to find out their policies on services to young people with disabilities. Launch a campaign for equal treatment.**
- **Press for the inclusion of training on the rights of children with disabilities in the training of all health professionals – doctors, nurses, dentists, physiotherapists, etc.**
- **Develop a series of case examples or vignettes relating to children's involvement in healthcare decisions. Organise focus groups with health professionals, and then with children with disabilities to explore how they react to the scenarios and how they differ in their perceptions of children's capacities for informed decision-making. Use the findings to raise awareness and sensitivity on the issues.**

## **Right to an adequate standard of living**

### **The key issues**

Disability is both a cause and an indirect consequence of poverty. Poor children are more likely to be malnourished and experience vitamin A and iodine deficiencies, more

vulnerable to infection, and less likely to have resistance to illness or access to healthcare. They are more likely to lack clean water and sanitation, and are more exposed to accidents. For example, in some rural communities, children are often left alone to care for younger children, in huts with open fires in the centre. This exposes small children to a high risk of burns and accidents. In some communities,

## The scale of poverty

In South Africa it is estimated that more than 80% of black children with disabilities live in extreme poverty, often in inhospitable environments with poor access to healthcare.<sup>99</sup> In rural areas, 98% of mothers with children with disabilities are unemployed, single and have had no education. And 99% of disabled people are unemployed.

In Nepal, the vast majority of disabled people are unemployed. One survey found that fewer than 3% of the respondents aged over 14 years had received any skills training to enable them to obtain work.<sup>100</sup> The survey also found that 76% were completely financially dependent on their families and a further 20% were only partially financially independent.

children are deliberately disabled in order to 'enhance' their effectiveness as beggars. Children who work illegally, or in hazardous occupations, are at very high risk of exposure to injuries and illness resulting in disability including burns, eye and hearing impairments, loss of body parts and respiratory and gastrointestinal illnesses.

Once a child has a disability, their mother is commonly abandoned, leaving her alone with the child. Evidence from all over the world indicates that where a family has a child with a disability, it is more likely to be headed by a single parent. The mother then faces a triple jeopardy. She cannot work easily with a disabled child to care for, the child's condition may necessitate extra expenditure, and the father, often the major breadwinner, is no longer there. In other words, she carries an increased burden of costs, while her productive capacity diminishes. In consequence, families with children with disabilities are disproportionately represented among the poorest in most societies. The difficulties are further compounded by the endemic failure in most developing countries to ensure the right of access to education for children with disabilities. This condemns them to a future life in which they lack the knowledge, skills and opportunities with which to rise out of poverty.

## The rights

### UN Convention on the Rights of the Child

**Article 26** – child's right to benefit from social security

**Article 27** – child's right to an adequate standard of living

**Article 32** – child labour

### UN Convention on the Rights of Persons with Disabilities

**Article 28** – adequate standard of living and social protection

Article 26 of the UNCRC recognises the right of children to benefit from social security provisions that take account of the circumstances of the child. Article 27 establishes the right of every child to a standard of living adequate for their proper development, and emphasises that parents have the primary responsibility to provide for their children. However, it also places responsibility on governments to assist parents in fulfilling

their child's right to an adequate standard of living, particularly where parents are poor. Governments must provide social security, material assistance, and help with food, clothing and housing. Article 28 of the CRPD reaffirms the right to an adequate standard of living. It also stresses the need for continual improvement of living conditions, in recognition both of the prevailing conditions of poverty facing most children with disabilities and of the need for progressive realisation of social and economic rights.

### **An adequate standard of living for proper development**

In advocating for an adequate standard of living for children with disabilities, it is important to draw on the provisions in both Conventions, as the UNCRC focuses on the particular issues facing children while the CRPD takes account of the specific circumstances of children with disabilities.

Article 27 of the UNCRC demands more than the prevention of absolute poverty. It requires

that children have access to a standard of living which will enable them to thrive and develop fully, and which is consistent with their human dignity. The wording of Article 27 recognises that children's development is strongly influenced by their living conditions. It lists different components of development including mental, spiritual, moral and social as well as physical, thus acknowledging that the obligations of parents and governments to children extend beyond the basics of food, clothing and housing.

Because the costs associated with disability may be higher than for other children, the CRPD recognises that children with disabilities may need a larger income to enable them to develop adequately. Article 28, therefore, sets out more specific obligations to provide for children with disabilities. Governments must:

- provide services, devices and assistance to address all disability-related needs. These might include, for example, extra laundry services, adaptations to the home, or additional care needs. The services must be affordable, and therefore should either

## **Empowering mothers of children with disabilities<sup>101</sup>**

DICAG (South Africa) has worked with the Department of Health in the Province of Mpumalanga to implement a nutrition programme. It was argued that children could learn and achieve more if they were better fed, and that the problems of poor nutrition derived not only from poverty but also from lack of knowledge and difficulties in physically feeding children. Accordingly, a pilot programme was designed to provide help with diets and feeding therapy. It was targeted at 400 children with disabilities.

The programme experienced considerable initial difficulties. Apart from some administrative problems, many parents felt angered by being told by professionals that their feeding practices needed changing. In response, the project held a series of workshops with food therapists and parents in which they did role play reversals. The outcome was a major learning experience for the professionals, who understood the need to be more sensitive to the knowledge and experience of the mothers, for whom correspondingly, the process was significantly empowering.

be free of charge to all children with disabilities, or subsidised through a process of means testing

- ensure access to social protection and poverty reduction programmes, in particular for women and girls. Specific social security provisions should be available to families with a child with a disability, in recognition of the additional costs associated with disability such as special food or diet, transport, extra heating, and wear and tear on clothing, and also of a parent's reduced opportunities to undertake paid employment when they are caring for a child with a disability. Social security benefits should also take into account the fact that many families with a disabled child are headed by a single parent, usually the mother, and there is no other breadwinner
- provide assistance with other disability-related expenses such as training, respite care and counselling.

In addition, the CRPD requires that the steps taken by governments to safeguard and promote an adequate standard of living must not discriminate on grounds of disability. In other words, any social protection measures must be available to children with disabilities without discrimination.

### **Protection from exploitative employment**

The UNCRC recognises the right of children to be protected from economic exploitation and from any work which is likely to be harmful to their development in any way, or to interfere with their education. It requires that governments take legislative, administrative, social and educational measures to ensure that the necessary protection is provided, including a minimum age for work, regulations on the hours and conditions of work and adequate penalties to ensure that the law is enforced. The International Labour Organization (ILO) Convention on the Worst Forms of Child

Labour introduces additional obligations to protect children.<sup>102</sup> It defines the following as the worst forms of child labour, and imposes obligations on governments to take action to ensure that they are eliminated:

- all forms of slavery or practices similar to slavery, such as the sale and trafficking of children, debt bondage and serfdom and forced or compulsory labour, including forced or compulsory recruitment of children for use in armed conflict
- the use, procuring or offering of a child for prostitution, for the production of pornography or for pornographic performances
- the use, procuring or offering of a child for illicit activities, in particular for the production and trafficking of drugs as defined in the relevant international treaties
- work which, by its nature or the circumstances in which it is carried out, is likely to harm the health, safety or morals of children.

Effective implementation of these obligations will serve to prevent many of the impairments that contribute to childhood disability, as well as to protect many children with disabilities from exposure to dangerous and exploitative work. Measures also need to be taken to address the practice of injuring children and forcing them to work as beggars; these measures include education and support for parents, awareness-raising and educational opportunities for children.

### **Child maintenance**

The UNCRC requires governments to introduce measures to enable a parent to claim maintenance from an absent parent in respect of any child for whom they are responsible. This is of particular importance, given the disproportionately high number of mothers who are caring alone for a child with a disability.

### **Advocacy tips on the right to an adequate standard of living**

- **Collect evidence on the experiences of poverty faced by families with a child with a disability and use the data to advocate for effective social security provisions for children with disabilities and their families.**
- **Encourage the media to make a television or radio programme following the life of a child with disabilities for a month to highlight the poverty experienced and the case for enhanced social protection.**
- **Launch a campaign to expose the practice of maiming children in order to make them work as beggars.**
- **Enlist the support of paediatricians and academics to undertake research into the injuries caused to working children and the scale of disability associated with child labour.**

## **Right to protection from all forms of violence and abuse**

### **The key issues**

Children with disabilities face a disproportionate risk of both physical and sexual violence and abuse, with some studies indicating that they are up to four times more likely to face violence than their non-disabled peers.<sup>103</sup> This vulnerability was acknowledged in the World Report on Violence against Children, published in 2005.<sup>104</sup> Violence against children with disabilities takes place in the family, in schools, in institutions, at work, on the streets, among peers and in the community. The causes are complex, but relate to widespread social attitudes of rejection and hostility to disability, lack of understanding as to the nature of disability, greater levels of dependency among children with disabilities, and the social isolation of children with disabilities. The violence is also linked to these children's reduced capacity to

challenge or protect themselves and the consequent comparative immunity from prosecution enjoyed by the abusers. In addition, children with disabilities are vulnerable to medical and scientific interventions undertaken without their consent and often without regard to their best interests.

However, to date, very little action has been taken to tackle violence against children with disabilities. Very few governments currently address the need to develop child protection services that are accessible or appropriate for them. For example, 'hotlines' and 'keep safe' programmes are largely irrelevant to many children with disabilities. They are less likely to have access to information about their rights, and therefore do not know what they are entitled to challenge. And even if they have that knowledge, there are few opportunities for reporting or challenging the abuse through accessible or effective complaints mechanisms.

## Examples of violence described by children with disabilities<sup>105</sup>

- deaf children being beaten for signing
- many blind children being abused within their families
- parents beating children who exhibit signs of mental illness, interpreting the behaviour as disobedience and wilfulness
- significant abuse of children with learning disabilities
- children with disabilities being rejected emotionally in families and abused because of their low status
- children being hidden away in the family home, treated like animals, sometimes even locked in cages, particularly in rural areas
- concerns over the widespread existence of sexual violence within families, which is denied or covered up because families are not willing to expose the problem
- difficulties for children in challenging abuse by teachers because of their high status in society
- problems of abuse by older disabled men.

## The rights

### UN Convention on the Rights of the Child

**Article 19** – child’s right to protection from all forms of violence

**Article 34** – sexual exploitation of children

**Article 37** – torture, degrading treatment and deprivation of liberty

**Article 39** – rehabilitation of child victims

**Optional Protocol to the Convention on the Rights of the Child on the sale of children, child prostitution and child pornography**

### UN Convention on the Rights of Persons with Disabilities

**Article 13** – access to justice

**Article 15** – freedom from torture, or cruel, inhuman or degrading treatment

**Article 16** – freedom from exploitation, violence and abuse

## Protection from violence

Article 19 of the UNCRC requires governments to introduce legislative, administrative, social and educational measures to protect children, including children with disabilities, from all forms of violence while in the care of a parent or other legal guardian. Article 16 of the CRPD also introduces obligations to take appropriate measures to prevent all forms of exploitation, violence and abuse. These measures need to be age and gender sensitive, taking account of the particular vulnerability of women and girls to violence and the need for targeted measures to address the situation of children. They also need to provide support for children with disabilities and their families and caregivers, including information and education on how to avoid, recognise and report instances of exploitation, violence and abuse.

The General Comments of the Committee on the Rights of the Child, both on children with disabilities and on protection from violence, provide more detailed examples of preventive measures which need to be implemented, including action to:<sup>106</sup>

- introduce legislation prohibiting all forms of violence, including corporal punishment

in all settings, including the home, family, schools, institutions and the juvenile justice system

- promote public awareness of positive, non-violent forms of parenting and education
- train and educate parents or others caring for the child to understand the risks and detect the signs of abuse of the child
- ensure that parents are vigilant about choosing caregivers and facilities for their children, and improve their ability to detect abuse
- provide and encourage support groups for parents, siblings and others taking care of the child to assist them in caring for their children and coping with their disabilities
- ensure that children and caregivers know that the child is entitled as a matter of right to be treated with dignity and respect and they have the right to complain to appropriate authorities if those rights are breached
- ensure that schools take all measures to combat school bullying and pay particular attention to children with disabilities, providing them with the necessary protection while maintaining their inclusion in the mainstream education system

## Barriers to getting justice<sup>107</sup>

Natasha had learning and communication disabilities and was attending a special needs school. Her mother suspected that she was being sexually abused when her daughter's behaviour began to show dramatic changes. She cried often, displayed anger and masturbated constantly. Despite repeated attempts to report it to the school, social services and the police, no investigation was undertaken. The behaviour

was attributed to Natasha's disability. Finally, after two years of struggle, the mother took her to a hospital and refused to leave until she was examined. She was found to have a vaginal discharge, her hymen was damaged and there were scars on her hymen at least two years old. Here was a child giving out the most powerful signals of sexual abuse, but because she had disabilities, she was not taken seriously.

## Unacceptable medical interventions<sup>108</sup>

Children with disabilities are subjected to clinical and pharmacological interventions that would be considered unacceptable if carried out on children without disabilities in the same community, with examples including electro-shock therapy, excessive medication and routine hysterectomies.

- ensure that institutions providing care for children with disabilities are staffed with specially trained personnel who have been properly screened, according to appropriate standards, regularly monitored and evaluated, and that the personnel have access to sensitive complaint mechanisms.

In addition, the World Report on Violence against Children provides detailed recommendations on actions necessary to implement obligations to protect the rights of children from all forms of violence, including children with disabilities.<sup>109</sup>

### No intervention without consent

Children with disabilities are particularly vulnerable to medical interventions to 'cure' their conditions, or to experimentation for the purposes of medical research. Article 15 of the CRPD explicitly prohibits such interventions without the free consent of the individual. The situation with children, however, is more complex. In many countries, the right of consent rests with parents until the child is an adult. In others, until they are judged to have appropriate capacity, children are not empowered to give consent. However, although the UNCRC does not directly address this issue, a holistic interpretation of its articles does indicate a need for considerable caution in

assuming that parents have a free hand to give consent unless there is a strong medical case for the intervention.

First, Article 3 requires that in any action concerning the child, their best interests must be the primary consideration. In other words, it is not acceptable to consent to an intervention, for example, to subject a child to painful corrective surgery on cosmetic grounds simply because the parents would like their child to look 'normal'. Nor should parents agree to experimentation on their child unless there would be specific medical benefits to the child.

In addition, it is necessary to take account of Articles 5 and 12. Article 5 stipulates that parents can only give direction and guidance in the exercise of a child's rights in accordance with his or her evolving capacities. In other words, as soon as the child has the capacity to understand the nature of the proposed intervention, and its implications, then it should be the child who gives consent, rather than the parent. And in all cases, where the child is capable of forming a view on the matter, they should be consulted and their views taken into account in accordance with their age and maturity. As an overarching principle, no consent should be given on a child's behalf for interventions that do not provide clear

clinical benefits, or where the decision could be deferred until the child has developed the capacity to give consent for himself or herself.

### **Independent inspection and monitoring**

Violence against children with disabilities often takes place within the very facilities and programmes designed to protect and assist them. Article 16(4) of the CRPD places an obligation on governments to ensure that all services for children with disabilities are effectively monitored. It is imperative that any monitoring systems are fully independent of the government, or the provider of the service, in order to ensure rigorous scrutiny and the power and authority to expose abuse of the rights of children with disabilities.

This requirement dovetails with the obligation in Article 3(3) of the UNCRC that institutions, services and facilities responsible for the care or protection of children must comply with standards established by competent authorities in relation to safety, health, suitability of staff and competent supervision. In addition, with regard to children with disabilities living in institutions, Article 25 of the UNCRC requires that there be periodic reviews of the treatment provided for the child. Thus, while Article 3 addresses the responsibility for monitoring the facility or institution, Article 25 requires the child's individual situation to be monitored. Both are necessary if the child is to be fully protected, and both stipulate that children with disabilities must be provided with the opportunity to participate in the process and, in confidence where necessary, to express their views and concerns.

### **Rehabilitation and social reintegration**

Both Article 16(4) of the CRPD and Article 39 of the UNCRC introduce obligations to promote the physical and psychological recovery and social reintegration of children with disabilities who have been victims of any form of exploitation or violence, including through the provision of protection services.

Both Conventions require that any recovery or reintegration processes must foster the health, welfare, self-respect and dignity of the child. They must also take into account gender-specific needs. The UNCRC includes reference to recovery following armed conflicts. This is of particular significance as not only are children with disabilities extremely vulnerable in situations of armed conflict, but conflict is also a major cause of disability, both through physical injuries and through psychological and emotional trauma. In addition, the Optional Protocol on the sale of children, child prostitution and child pornography requires the introduction of measures to rehabilitate child victims of exploitation.<sup>110</sup>

The Committee on the Rights of the Child has made it clear that measures required under Article 39 should address all children who are victims of cruel, inhuman or degrading treatment, or physical, mental or sexual violence, as well as child victims including refugees, child labourers, children who have been sold or trafficked, and those involved in the juvenile justice system.<sup>111</sup> Children with disabilities may be represented among all these groups, and the CRPD requires that targeted measures be introduced to address their specific needs for rehabilitation. Such programmes should be interdisciplinary and be provided with adequate support and funding.

The Committee on the Rights of the Child also emphasises the importance of ensuring that children who are in need of protection are not treated as offenders. In many countries, for example, legislation dealing with abandonment, vagrancy, prostitution, migrant status, truancy or runaways criminalises children rather than dealing with them as children in need of child protection. A non-punitive approach is required, which might include the following measures, depending on the nature of the exploitation, violence or abuse:

- social, medical and psychological counselling for victims and their families

- access to education, healthcare, means of financial support, legal aid and a safe environment
- provision of community development centres, recreational facilities and services responsive to the special problems of children who are at risk
- gender- and disability-sensitive training provided to health professionals, teachers, social workers and relevant NGOs
- action to prevent and remove social stigmatisation of child victims and their families
- programmes to facilitate recovery and reintegration within families and communities wherever possible
- promotion of positive means of livelihood for child victims and their families so as to prevent further risk of exploitation and abuse
- victim compensation and assistance programmes.

### **Identification, investigation and prosecution of offenders**

Article 19 of the UNCRC requires that protective measures for identification, reporting, referral, investigation, treatment and follow-up of child abuse are put in place.

However, children with disabilities face particular problems at all stages of the child protection process. Because they are often hidden from public view, any abuse they experience is less likely to be witnessed or recognised by the wider family or neighbours. Indeed, the prejudice against children with disabilities is such that there is less likely to be concern over potential violence towards them. Dependency on carers and communication difficulties can create barriers in reporting abuse for many children with disabilities. Many children fear retaliation, but this is particularly acute for children with disabilities. Once abuse is reported, children with disabilities are often not considered to be reliable witnesses. For example, in some countries, blind people are automatically precluded from giving evidence. Furthermore, they are rarely provided with the support needed to ensure that they are able to communicate their experiences to the court.

Accordingly, Article 16 of the CRPD introduces additional obligations on State Parties to introduce specific measures to ensure that violence against children with disabilities is identified, investigated and, where appropriate, prosecuted. It requires that any legislation and

## **Impunity for abusers<sup>112</sup>**

In one residential school for deaf children in a rural area in South Africa, a number of girls had been regularly raped by the headteacher over a period of years. When they finally complained and were taken seriously, the headteacher was charged with assault and brought to court. However, he told the children that if they testified against him, their hands would fall off. The hands of deaf children, whose language is signing, are their link with the world. The children believed him and withdrew their charges. The case was dropped.

policies must be disability, gender and child focused. This will necessitate:

- legislative measures to punish and remove perpetrators from the home and ensure that the child is not deprived of his or her family and can continue to live in a safe and healthy environment
- accessible and safe disability and child-sensitive complaint mechanisms
- access to the necessary communication, physical and other supports to enable them to participate in legal proceedings.

### **Advocacy tips on the right to protection from all forms of violence<sup>113</sup>**

- **Gather evidence of prevalence and severity of physical and sexual violence against children with disabilities.**
- **Launch a high-profile campaign to highlight the scale of the violence.**
- **Lobby the government to prohibit all forms of violence, including all corporal punishment, sexual violence and harmful traditional practices.**
- **Lobby the government to introduce legislation providing full protection for children with disabilities in residential institutions, including schools, together with an independent inspectorate with powers to review all aspects of care.**
- **Develop resources for children with disabilities on their right to protection from all forms of violence, and disseminate through media, schools, health facilities and youth associations.**
- **Review the child protection procedures that exist and assess their accessibility and appropriateness for children with disabilities.**
- **Support children with disabilities to take cases of complaint to the appropriate authorities when their right to protection from all forms of violence is violated.**

## **Right to justice and liberty**

### **The key issues**

Children with disabilities face real challenges in realising their rights within the justice system. The World Report on Violence against

Children highlighted the fact that “children with disabilities are disproportionately represented in the criminal justice system. Furthermore, once in the system, they often fare far worse than their non-disabled peers.”<sup>114</sup> For example, evidence in the USA indicates that whereas the overall prevalence of children with disabilities

is 9%, it is estimated that they represent 32% of children detained in the criminal justice system.<sup>115</sup> Other research suggests that as many as 90% of young people in detention meet the criteria for one or more psychosocial conditions.<sup>116</sup>

The difficulties can arise at all stages of the process. Lack of training among staff throughout the system, lack of awareness of the nature or implications of disability, lack of accommodation to their communication needs, inaccessible buildings, compounded by negative and hostile attitudes, all serve to create almost insuperable barriers. As a result, children with disabilities are at particular risk of failing to get a fair hearing. The police, when arresting a child or young person, often fail to recognise that the child has a disability, for example, deafness or an intellectual impairment. The child's behaviour may be read as insolence, refusal to cooperate or indifference, all of which may be punished by the police or used in evidence against the child. The child may have difficulty in communicating their personal details, resulting in a failure to contact family members. If the child has legal representation (and, of course, many do not) their lawyer may not be able to communicate effectively with them, with the very real possibility of the facts of the case not being presented accurately to the court, and an inappropriate sentence being imposed. If children with disabilities are punished with detention, the prison may be inaccessible, appropriate medication may not be available, the child may not be able to communicate with staff and he or she will be particularly vulnerable to bullying by both prison wardens and other inmates, with no means of challenging the abuse.

## The rights

### **UN Convention on the Rights of the Child**

**Article 12** – respect for the views of the child

**Article 37** – torture, degrading treatment and deprivation of liberty

**Article 40** – administration of juvenile justice

### **UN Convention on the Rights of Persons with Disabilities**

**Article 13** – access to justice

**Article 14** – liberty and security of the person

## Protection in the juvenile justice system

Articles 37 and 40 of the UNCRC contain detailed provisions establishing the rights of children to full protection within the juvenile justice system. These provisions must be implemented without discrimination for children with disabilities. The Committee on the Rights of the Child recognises the difficulties faced by children with disabilities, and has outlined additional recommendations for governments to ensure their greater protection when in conflict with the law:<sup>117</sup>

- Children with disabilities must be interviewed using appropriate languages or forms of communication.
- Police, social workers, lawyers and advocates, prosecutors and judges must have appropriate training.

- Children with disabilities, like other children, should be dealt with as far as possible without resorting to formal legal procedures, but where it is necessary, efforts must be made to ensure that they have access to information about the juvenile justice system and their rights within it.
- Deprivation of liberty should only be considered where a treatment programme to address the problems resulting in the crime is being provided. In such cases, the institution must have appropriate facilities and trained staff. In making such decisions, the competent authorities should make sure that the human rights and legal safeguards of the children are fully respected.

Article 13 of the CRPD strengthens the provisions of the UNCRC by translating some of these recommendations into legal obligations. It requires that measures be taken to help children with disabilities get access to justice (see below). It also specifically lays down that all those working in the field of administration of justice, including police and prison staff, must be appropriately trained.

### **Access to justice**

The right of access to the justice system applies equally where children with disabilities themselves are seeking access to justice, for example, following abuse or ill treatment. The CRPD requires that they must be able to access the system on an equal basis with others. This means governments must provide them with relevant support to enable them to participate in all legal proceedings, including as witnesses, and at investigative and other preliminary stages. This might include interpreting, access to sign language, access to information in accessible and age-appropriate forms, physical access to the courts, sufficient time made available to ensure the child fully understands the court procedures, video-taped interviews, and forms of questioning that promote children's understanding and capacity to express themselves.

### **Advocacy tips on the right to justice and liberty**

- **Develop and provide training for all professionals working in the justice system on the rights of children with disabilities.**
- **Develop guidance on how to establish disability- and child-friendly courts.**
- **Encourage the government to undertake research on children in detention to find out how many have disabilities and the effect that this had on their sentence and subsequent experience in detention.**

## **Rights in situations of emergency and conflict**

### **The key issues**

Children with disabilities suffer disproportionately in situations of conflict and humanitarian disaster. They are often the first to be neglected in times of scarcity, are frequently abandoned when families are fleeing a conflict area and the last to receive emergency relief and support.<sup>118</sup> Conflict also creates more children with disabilities, especially in countries where the conflict involves deliberate maiming and the use of landmines. Even in cases where mines are not involved, conflict disrupts routine activities such as healthcare and immunisations, and can result in an upsurge in disabling diseases such as polio and trachoma. Conflict sometimes leads to malnutrition and even famine when communities are isolated, farming is abandoned or people are forced to flee into resource-poor areas. This can result in both cognitive and physical stunting as well as nutritional deficiency-related disabilities such as blindness. Children required to carry heavy loads for the armed forces may also suffer from injuries or deformation to their bones that result in later disabilities.

## The rights

### **UN Convention on the Rights of the Child**

**Article 38** – protection of children affected by armed conflict

**Optional Protocol to the Convention on the Rights of the Child on the involvement of children in armed conflict**

### **UN Convention on the Rights of Persons with Disabilities**

**Article 11** – situations of risk and humanitarian emergencies

The UNCRC requires governments to ensure respect for the rules of humanitarian law in situations of armed conflict, and to take all possible measures to provide care and protection of children in conflict situations. The Committee on the Rights of the Child urges governments to ratify the Optional Protocol on children and armed conflict which requires that States take all possible measures to ensure that children under 18 years are not recruited into the armed forces.<sup>115</sup> In addition, it stresses that special attention must be paid to the recovery and rehabilitation of children who are disabled as a result of armed conflicts.

The CRPD introduces additional specific obligations to protect the rights of children with disabilities. The preamble emphasises the importance of respect for relevant human rights standards if the rights of people with disabilities are to be protected in situations of conflict and foreign occupation. It also requires States to take all possible measures to ensure their protection in situations of risk, including armed conflict, humanitarian emergencies and natural disasters.

Together, the obligations in the two Conventions mean that, in natural disasters or humanitarian emergencies, action needs to be taken to:

- take account of the needs of children with disabilities in emergency planning and training
- address their needs in the design of systems for evacuation, shelter and emergency communications
- involve people, including children with disabilities, in the full range of emergency response and relief efforts
- focus efforts on prevention of disabling conditions and early identification of these conditions
- reunify children with families and provide families with support
- provide physical rehabilitation and psychosocial services for children
- provide children with access to education and practical training in inclusive settings.

### **Advocacy tips on rights in situations of emergency and conflict**

- **Work with the relevant UN agencies to ensure that in emergency preparedness programmes, the rights of children with disabilities are fully recognised and incorporated.**
- **Advocate to ensure that assistance to children who are victims of landmines addresses: data collection, emergency and continuing medical care, physical rehabilitation and prosthetics, psychological support and social reintegration, economic reintegration, and disability laws and policies.**
- **Consult with children with disabilities in post-emergency situations on their experiences and ideas on what is needed to ensure their protection in such situations.**

# Appendix I: The UN Convention on the Rights of Persons with Disabilities and Optional Protocol

## Preamble

*The States Parties to the present Convention,*

*(a) Recalling* the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world,

*(b) Recognizing* that the United Nations, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind,

*(c) Reaffirming* the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination,

*(d) Recalling* the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention against

Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Rights of the Child, and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families,

*(e) Recognizing* 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,

*(f) Recognizing* the importance of the principles and policy guidelines contained in the World Programme of Action concerning Disabled Persons and in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in influencing the promotion, formulation and evaluation of the policies, plans, programmes and actions at the national, regional and international levels to further equalize opportunities for persons with disabilities,

*(g) Emphasizing* the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development,

*(h) Recognizing also* that discrimination against any person on the basis of disability

is a violation of the inherent dignity and worth of the human person,

(i) *Recognizing further* the diversity of persons with disabilities,

(j) *Recognizing* the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support,

(k) *Concerned* that, despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world,

(l) *Recognizing* the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries,

(m) *Recognizing* the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty,

(n) *Recognizing* the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,

(o) *Considering* 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,

(p) *Concerned* about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status,

(q) *Recognizing* that women and girls with disabilities are often at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation,

(r) *Recognizing* that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child,

(s) *Emphasizing* the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities,

(t) *Highlighting* the fact that the majority of persons with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the negative impact of poverty on persons with disabilities,

(u) *Bearing in mind* that conditions of peace and security based on full respect for the purposes and principles contained in the Charter of the United Nations and observance of applicable human rights instruments are indispensable for the full protection of persons with disabilities, in particular during armed conflicts and foreign occupation,

(v) *Recognizing* the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms,

(w) *Realizing* that the individual, having duties to other individuals and to the community to which he or she belongs, is under a responsibility to strive for the promotion and observance of the rights recognized in the International Bill of Human Rights,

(x) *Convinced* that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary

protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities,

(y) *Convinced* that a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries,

*Have agreed* as follows:

## Article 1

### Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. 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.

## Article 2

### Definitions

For the purposes of the present Convention:

“Communication” includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology; “Language” includes spoken and signed languages and other forms of non-spoken languages;

“Discrimination on the basis of disability” 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;

“Reasonable accommodation” means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

“Universal design” means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

“Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

## Article 3

### General principles

The principles of the present Convention shall be:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;

- (f) Accessibility;
- (g) Equality between men and women;
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

## Article 4

### General obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

- (a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
- (b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- (c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
- (d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;
- (e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;
- (f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities,

to promote their availability and use, and to promote universal design in the development of standards and guidelines;

(g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

(h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;

(i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.

2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

3. 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 organizations.

4. Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force

for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.

5. The provisions of the present Convention shall extend to all parts of federal States without any limitations or exceptions.

## **Article 5**

### **Equality and non-discrimination**

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

## **Article 6**

### **Women with disabilities**

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal

enjoyment by them of all human rights and fundamental freedoms.

2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

## **Article 7**

### **Children with disabilities**

1. States Parties shall take all necessary 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, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

## **Article 8**

### **Awareness-raising**

1. States Parties undertake to adopt immediate, effective and appropriate measures:

(a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;

(b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;

(c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:

(a) Initiating and maintaining effective public awareness campaigns designed:

(i) To nurture receptiveness to the rights of persons with disabilities;

(ii) To promote positive perceptions and greater social awareness towards persons with disabilities;

(iii) To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;

(b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;

(c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;

(d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

## Article 9

### Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

(a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;

(b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures:

(a) To develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;

(b) To ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;

(c) To provide training for stakeholders on accessibility issues facing persons with disabilities;

(d) To provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;

(e) To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;

(f) To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

(g) To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;

(h) To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

## **Article 10**

### **Right to life**

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

## **Article 11**

### **Situations of risk and humanitarian emergencies**

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

## **Article 12**

### **Equal recognition before the law**

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity

provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

## **Article 13**

### **Access to justice**

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.
2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

## Article 14

### Liberty and security of person

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:

- (a) Enjoy the right to liberty and security of person;
- (b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of the present Convention, including by provision of reasonable accommodation.

## Article 15

### Freedom from torture or cruel, inhuman or degrading treatment or punishment

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

## Article 16

### Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

## **Article 17**

### **Protecting the integrity of the person**

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

## **Article 18**

### **Liberty of movement and nationality**

1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:

- (a) Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;
- (b) Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;
- (c) Are free to leave any country, including their own;
- (d) Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country.

2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

## **Article 19**

### **Living independently and being included in the community**

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

## **Article 20**

### **Personal mobility**

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

(a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;

(b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;

(c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;

(d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

## Article 21

### Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

(a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;

(c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services

in accessible and usable formats for persons with disabilities;

(d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;

(e) Recognizing and promoting the use of sign languages.

## Article 22

### Respect for privacy

1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

## Article 23

### Respect for home and the family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

(b) The rights of persons with disabilities to decide freely and responsibly on the number

and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

## Article 24

### Education

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

(a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

(b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;

(c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

(a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

(b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

(c) Reasonable accommodation of the individual's requirements is provided;

(d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

(e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

- (a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
- (b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
- (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

## Article 25

### Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

## Article 26

### Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

- (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
- (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

## Article 27

### Work and employment

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.

States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

- (a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;
- (b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;
- (c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;
- (d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;
- (e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;
- (f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
- (g) Employ persons with disabilities in the public sector;
- (h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
- (i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

- (j) Promote the acquisition by persons with disabilities of work experience in the open labour market;
- (k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

## Article 28

### Adequate standard of living and social protection

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

- (a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
- (b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
- (c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability

related expenses, including adequate training, counselling, financial assistance and respite care;

(d) To ensure access by persons with disabilities to public housing programmes;

(e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

## Article 29

### Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:

(a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:

- (i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
- (ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;
- (iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;

(b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

- (i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
- (ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

## **Article 30**

### **Participation in cultural life, recreation, leisure and sport**

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:

- (a) Enjoy access to cultural materials in accessible formats;
- (b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;
- (c) Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.

3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:

- (a) To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
- (b) To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;
- (c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
- (d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
- (e) To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

## **Article 31**

### **Statistics and data collection**

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

- (a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
- (b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

## Article 32

### International cooperation

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

- (a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;
- (b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;

- (c) Facilitating cooperation in research and access to scientific and technical knowledge;
- (d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

## Article 33

### National implementation and monitoring

1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

## Article 34

### Committee on the Rights of Persons with Disabilities

1. There shall be established a Committee on the Rights of Persons with Disabilities (hereafter referred to as “the Committee”), which shall carry out the functions hereinafter provided.

2. The Committee shall consist, at the time of entry into force of the present Convention, of twelve experts. After an additional sixty ratifications or accessions to the Convention, the membership of the Committee shall increase by six members, attaining a maximum number of eighteen members.

3. The members of the Committee shall serve in their personal capacity and shall be of high moral standing and recognized competence and experience in the field covered by the present Convention. When nominating their candidates, States Parties are invited to give due consideration to the provision set out in article 4, paragraph 3, of the present Convention.

4. The members of the Committee shall be elected by States Parties, consideration being given to equitable geographical distribution, representation of the different forms of civilization and of the principal legal systems, balanced gender representation and participation of experts with disabilities.

5. The members of the Committee shall be elected by secret ballot from a list of persons nominated by the States Parties from among their nationals at meetings of the Conference of States Parties. At those meetings, for which two thirds of States Parties shall constitute a quorum, the persons elected to the Committee shall be those who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

6. The initial election shall be held no later than six months after the date of entry into force of the present Convention. At least four months before the date of each election, the Secretary-General of the United Nations shall address a letter to the States Parties inviting them to submit the nominations within two months. The Secretary-General shall subsequently prepare a list in alphabetical order of all persons thus nominated, indicating the State Parties which have nominated them, and shall submit it to the States Parties to the present Convention.

7. The members of the Committee shall be elected for a term of four years. They shall be eligible for re-election once. However, the term of six of the members elected at the first election shall expire at the end of two years; immediately after the first election, the names of these six members shall be chosen by lot by the chairperson of the meeting referred to in paragraph 5 of this article.

8. The election of the six additional members of the Committee shall be held on the occasion of regular elections, in accordance with the relevant provisions of this article.

9. If a member of the Committee dies or resigns or declares that for any other cause she or he can no longer perform her or his duties, the State Party which nominated the member shall appoint another expert possessing the qualifications and meeting the requirements set out in the relevant provisions of this article, to serve for the remainder of the term.

10. The Committee shall establish its own rules of procedure.

11. The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Convention, and shall convene its initial meeting.

12. With the approval of the General Assembly of the United Nations, the members of the Committee established under the present Convention shall receive emoluments from United Nations resources on such terms and conditions as the Assembly may decide, having regard to the importance of the Committee's responsibilities.

13. The members of the Committee shall be entitled to the facilities, privileges and immunities of experts on mission for the United Nations as laid down in the relevant sections of the Convention on the Privileges and Immunities of the United Nations.

## Article 35

### Reports by States Parties

1. Each State Party shall submit to the Committee, through the Secretary-General of the United Nations, a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned.

2. Thereafter, States Parties shall submit subsequent reports at least every four years and further whenever the Committee so requests.

3. The Committee shall decide any guidelines applicable to the content of the reports.

4. A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports, repeat information previously provided. When preparing reports to the Committee, States Parties are invited to consider doing so in an open and transparent process and to give due consideration to the provision set out in article 4, paragraph 3, of the present Convention.

5. Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Convention.

## Article 36

### Consideration of reports

1. Each report shall be considered by the Committee, which 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 State Party may respond with any information it chooses to the Committee. The Committee may request further information from States Parties relevant to the implementation of the present Convention.

2. If a State Party is significantly overdue in the submission of a report, the Committee may notify the State Party concerned of the need to examine the implementation of the present Convention in that State Party, on the basis of reliable information available to the Committee, if the relevant report is not submitted within three months following the notification. The Committee shall invite the State Party concerned to participate in such examination. Should the State Party respond by submitting the relevant report, the provisions of paragraph 1 of this article will apply.

3. The Secretary-General of the United Nations shall make available the reports to all States Parties.

4. States Parties shall make their reports widely available to the public in their own countries and facilitate access to the suggestions and general recommendations relating to these reports.

5. The Committee shall transmit, as it may consider appropriate, to the specialized agencies, funds and programmes of the United Nations, and other competent bodies, reports

from States Parties in order to address a request or indication of a need for technical advice or assistance contained therein, along with the Committee's observations and recommendations, if any, on these requests or indications.

## **Article 37**

### **Cooperation between States Parties and the Committee**

1. Each State Party shall cooperate with the Committee and assist its members in the fulfilment of their mandate.

2. In its relationship with States Parties, the Committee shall give due consideration to ways and means of enhancing national capacities for the implementation of the present Convention, including through international cooperation.

## **Article 38**

### **Relationship of the Committee with other bodies**

In order to foster the effective implementation of the present Convention and to encourage international cooperation in the field covered by the present Convention:

(a) The specialized agencies and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their mandate. The Committee may invite the specialized agencies and other competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates. The Committee may invite specialized agencies and other United Nations organs to submit reports on

the implementation of the Convention in areas falling within the scope of their activities;

(b) The Committee, as it discharges its mandate, shall consult, as appropriate, other relevant bodies instituted by international human rights treaties, with a view to ensuring the consistency of their respective reporting guidelines, suggestions and general recommendations, and avoiding duplication and overlap in the performance of their functions.

## **Article 39**

### **Report of the Committee**

The Committee shall report every two years to the General Assembly and to the Economic and Social Council on its activities, and may make suggestions and general recommendations based on the examination of reports and information received from the States Parties. Such suggestions and general recommendations shall be included in the report of the Committee together with comments, if any, from States Parties.

## **Article 40**

### **Conference of States Parties**

1. The States Parties shall meet regularly in a Conference of States Parties in order to consider any matter with regard to the implementation of the present Convention.

2. No later than six months after the entry into force of the present Convention, the Conference of States Parties shall be convened by the Secretary-General of the United Nations. The subsequent meetings shall be convened by the Secretary-General biennially or upon the decision of the Conference of States Parties.

## Article 41

### Depositary

The Secretary-General of the United Nations shall be the depositary of the present Convention.

## Article 42

### Signature

The present Convention shall be open for signature by all States and by regional integration organizations at United Nations Headquarters in New York as of 30 March 2007.

## Article 43

### Consent to be bound

The present Convention shall be subject to ratification by signatory States and to formal confirmation by signatory regional integration organizations. It shall be open for accession by any State or regional integration organization which has not signed the Convention.

## Article 44

### Regional integration organizations

1. "Regional integration organization" shall mean an organization constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by the present Convention. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by the present Convention. Subsequently, they shall inform the depositary of any substantial modification in the extent of their competence.

2. References to "States Parties" in the present Convention shall apply to such organizations within the limits of their competence.

3. For the purposes of article 45, paragraph 1, and article 47, paragraphs 2 and 3, of the present Convention, any instrument deposited by a regional integration organization shall not be counted.

4. Regional integration organizations, in matters within their competence, may exercise their right to vote in the Conference of States Parties, with a number of votes equal to the number of their member States that are Parties to the present Convention. Such an organization shall not exercise its right to vote if any of its member States exercises its right, and vice versa.

## Article 45

### Entry into force

1. The present Convention shall enter into force on the thirtieth day after the deposit of the twentieth instrument of ratification or accession.

2. For each State or regional integration organization ratifying, formally confirming or acceding to the present Convention after the deposit of the twentieth such instrument, the Convention shall enter into force on the thirtieth day after the deposit of its own such instrument.

## Article 46

### Reservations

1. Reservations incompatible with the object and purpose of the present Convention shall not be permitted.

2. Reservations may be withdrawn at any time.

## **Article 47**

### **Amendments**

1. Any State Party may propose an amendment to the present Convention and submit it to the Secretary-General of the United Nations. The Secretary-General shall communicate any proposed amendments to States Parties, with a request to be notified whether they favour a conference of States Parties for the purpose of considering and deciding upon the proposals. In the event that, within four months from the date of such communication, at least one third of the States Parties favour such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of two thirds of the States Parties present and voting shall be submitted by the Secretary-General to the General Assembly of the United Nations for approval and thereafter to all States Parties for acceptance.

2. An amendment adopted and approved in accordance with paragraph 1 of this article shall enter into force on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment. Thereafter, the amendment shall enter into force for any State Party on the thirtieth day following the deposit of its own instrument of acceptance. An amendment shall be binding only on those States Parties which have accepted it.

3. If so decided by the Conference of States Parties by consensus, an amendment adopted and approved in accordance with paragraph 1

of this article which relates exclusively to articles 34, 38, 39 and 40 shall enter into force for all States Parties on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment.

## **Article 48**

### **Denunciation**

A State Party may denounce the present Convention by written notification to the Secretary-General of the United Nations. The denunciation shall become effective one year after the date of receipt of the notification by the Secretary-General.

## **Article 49**

### **Accessible format**

The text of the present Convention shall be made available in accessible formats.

## **Article 50**

### **Authentic texts**

The Arabic, Chinese, English, French, Russian and Spanish texts of the present Convention shall be equally authentic.

IN WITNESS THEREOF the undersigned plenipotentiaries, being duly authorized thereto by their respective Governments, have signed the present Convention.

## Optional Protocol to the Convention on the Rights of Persons with Disabilities

*The States Parties to the present Protocol have agreed as follows:*

### Article 1

1. A State Party to the present Protocol (“State Party”) recognizes the competence of the Committee on the Rights of Persons with Disabilities (“the Committee”) to receive and consider communications from or on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention.

2. No communication shall be received by the Committee if it concerns a State Party to the Convention that is not a party to the present Protocol.

### Article 2

The Committee shall consider a communication inadmissible when:

- (a) The communication is anonymous;
- (b) The communication constitutes an abuse of the right of submission of such communications or is incompatible with the provisions of the Convention;
- (c) The same matter has already been examined by the Committee or has been or is being examined under another procedure of international investigation or settlement;
- (d) All available domestic remedies have not been exhausted. This shall not be the rule where the application of the remedies is unreasonably prolonged or unlikely to bring effective relief;
- (e) It is manifestly ill-founded or not sufficiently substantiated; or when

(f) The facts that are the subject of the communication occurred prior to the entry into force of the present Protocol for the State Party concerned unless those facts continued after that date.

### Article 3

Subject to the provisions of article 2 of the present Protocol, the Committee shall bring any communications submitted to it confidentially to the attention of the State Party. Within six months, the receiving State shall submit to the Committee written explanations or statements clarifying the matter and the remedy, if any, that may have been taken by that State.

### Article 4

1. At any time after the receipt of a communication and before a determination on the merits has been reached, the Committee may transmit to the State Party concerned for its urgent consideration a request that the State Party take such interim measures as may be necessary to avoid possible irreparable damage to the victim or victims of the alleged violation.

2. Where the Committee exercises its discretion under paragraph 1 of this article, this does not imply a determination on admissibility or on the merits of the communication.

### Article 5

The Committee shall hold closed meetings when examining communications under the present Protocol. After examining a communication, the Committee shall forward its suggestions and recommendations, if any, to the State Party concerned and to the petitioner.

## Article 6

1. If the Committee receives reliable information indicating grave or systematic violations by a State Party of rights set forth in the Convention, the Committee shall invite that State Party to cooperate in the examination of the information and to this end submit observations with regard to the information concerned.

2. Taking into account any observations that may have been submitted by the State Party concerned as well as any other reliable information available to it, the Committee may designate one or more of its members to conduct an inquiry and to report urgently to the Committee. Where warranted and with the consent of the State Party, the inquiry may include a visit to its territory.

3. After examining the findings of such an inquiry, the Committee shall transmit these findings to the State Party concerned together with any comments and recommendations.

4. The State Party concerned shall, within six months of receiving the findings, comments and recommendations transmitted by the Committee, submit its observations to the Committee.

5. Such an inquiry shall be conducted confidentially and the cooperation of the State Party shall be sought at all stages of the proceedings.

## Article 7

1. The Committee may invite the State Party concerned to include in its report under article 35 of the Convention details of any measures taken in response to an inquiry conducted under article 6 of the present Protocol.

2. The Committee may, if necessary, after the end of the period of six months referred to in article 6, paragraph 4, invite the State Party concerned to inform it of the measures taken in response to such an inquiry.

## Article 8

Each State Party may, at the time of signature or ratification of the present Protocol or accession thereto, declare that it does not recognize the competence of the Committee provided for in articles 6 and 7.

## Article 9

The Secretary-General of the United Nations shall be the depositary of the present Protocol.

## Article 10

The present Protocol shall be open for signature by signatory States and regional integration organizations of the Convention at United Nations Headquarters in New York as of 30 March 2007.

## Article 11

The present Protocol shall be subject to ratification by signatory States of the present Protocol which have ratified or acceded to the Convention. It shall be subject to formal confirmation by signatory regional integration organizations of the present Protocol which have formally confirmed or acceded to the Convention. It shall be open for accession by any State or regional integration organization which has ratified, formally confirmed or acceded to the Convention and which has not signed the Protocol.

## Article 12

1. “Regional integration organization” shall mean an organization constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by the Convention and the present Protocol. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by the Convention and the present Protocol. Subsequently, they shall inform the depositary of any substantial modification in the extent of their competence.

2. References to “States Parties” in the present Protocol shall apply to such organizations within the limits of their competence.

3. For the purposes of article 13, paragraph 1, and article 15, paragraph 2, of the present Protocol, any instrument deposited by a regional integration organization shall not be counted.

4. Regional integration organizations, in matters within their competence, may exercise their right to vote in the meeting of States Parties, with a number of votes equal to the number of their member States that are Parties to the present Protocol. Such an organization shall not exercise its right to vote if any of its member States exercises its right, and vice versa.

## Article 13

1. Subject to the entry into force of the Convention, the present Protocol shall enter into force on the thirtieth day after the deposit of the tenth instrument of ratification or accession.

2. For each State or regional integration organization ratifying, formally confirming or acceding to the present Protocol after the deposit of the tenth such instrument,

the Protocol shall enter into force on the thirtieth day after the deposit of its own such instrument.

## Article 14

1. Reservations incompatible with the object and purpose of the present Protocol shall not be permitted.

2. Reservations may be withdrawn at any time.

## Article 15

1. Any State Party may propose an amendment to the present Protocol and submit it to the Secretary-General of the United Nations. The Secretary-General shall communicate any proposed amendments to States Parties, with a request to be notified whether they favour a meeting of States Parties for the purpose of considering and deciding upon the proposals. In the event that, within four months from the date of such communication, at least one third of the States Parties favour such a meeting, the Secretary-General shall convene the meeting under the auspices of the United Nations. Any amendment adopted by a majority of two thirds of the States Parties present and voting shall be submitted by the Secretary-General to the General Assembly of the United Nations for approval and thereafter to all States Parties for acceptance.

2. An amendment adopted and approved in accordance with paragraph 1 of this article shall enter into force on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment. Thereafter, the amendment shall enter into force for any State Party on the thirtieth day following the deposit of its own instrument of acceptance. An amendment shall be binding only on those States Parties which have accepted it.

## **Article 16**

A State Party may denounce the present Protocol by written notification to the Secretary-General of the United Nations. The denunciation shall become effective one year after the date of receipt of the notification by the Secretary-General.

## **Article 17**

The text of the present Protocol shall be made available in accessible formats.

## **Article 18**

The Arabic, Chinese, English, French, Russian and Spanish texts of the present Protocol shall be equally authentic.

IN WITNESS THEREOF the undersigned plenipotentiaries, being duly authorized thereto by their respective Governments, have signed the present Protocol.

# Appendix 2: Useful resources

## I Key links

Key documents on disability

<http://www.un.org/disabilities/default.asp?id=182>

V Pineda, *It's about Ability: An explanation of the Convention on the Rights of Persons with Disabilities*, UNICEF, 2008

[http://www.unicef.org/Child\\_friendly\\_CRPD.doc](http://www.unicef.org/Child_friendly_CRPD.doc)

UN Enable Rights and Dignity for Persons with Disability: Primary UN source of information on disability

<http://www.un.org/disabilities/index.asp>

Young Voices on the UN Convention on the Rights and Dignity of Persons with Disability

<http://www.lcint.webbler.co.uk/?lid=3103>

## 2 Useful global organisations/ links/websites

Action on Disability and Development

<http://www.add.org.uk/>

Bond Disability and Development Working Group

<http://www.bond.org.uk/wgroups/disability/index.html>

Children's Rights Information Network (CRIN) Section on disability

<http://www.crin.org/themes/ViewTheme.asp?id=5>

Disability Awareness in Action

[www.daa.org.uk](http://www.daa.org.uk)

Disability Funders Network

[http://www.disabilityfunders.org/un\\_convention#housereres](http://www.disabilityfunders.org/un_convention#housereres)

Disabled Peoples' International

<http://www.icrpd.net/implementation/en/aboutus.htm>

Handicap International

<http://www.handicap-international.org/>

IDEA – International Disability Equality Agency

<http://www.disabilityequality.org>

Inclusion International

<http://www.inclusion-international.org/en/>

International Disability Alliance

<http://www.internationaldisabilityalliance.org/>

International Disability and Development Consortium

[http://www.iddc.org.uk/dis\\_dev/topics.shtml](http://www.iddc.org.uk/dis_dev/topics.shtml)

Leonard Cheshire Disability – International

<http://www.lcint.org/>

Rehabilitation International

<http://www.riglobal.org/>

World Blind Union

<http://www.worldblindunion.org>

World Federation of the Deaf  
<http://www.wfdeaf.org>

World Network of Users and Survivors  
of Psychiatry  
<http://www.wnusp.net>

### 3 Toolkits/guidance for implementing the CRPD

*Advocacy Services for People with Mental Health  
Problems and Intellectual Disabilities: Guidance and  
model policies*, Mental Disability Advocacy  
Centre, 2006  
<http://www.mdac.info/en/Advocacy-Services>

*Convention on the Rights of Persons with  
Disabilities: Its implementation and Relevance  
for the World Bank*, Katherine Guernsey et al,  
World Bank June 2007  
[http://web.worldbank.org/WBSITE/EXTERNAL/  
TOPICS/EXTSOCIALPROTECTION/  
EXTDISABILITY](http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY)

*Disability Rights Advocacy Workbook*, A Shettle,  
Survivors Corps, 2008  
[www.landminesurvivors.org](http://www.landminesurvivors.org)

Disability Rights and Policies – References  
documents and resources, Handicap International  
[http://www.handicap-international.fr/  
bibliographie-handicap/FrameUS.htm](http://www.handicap-international.fr/bibliographie-handicap/FrameUS.htm)

*Disability Rights Convention: Ratification Campaign  
handbook*, Landmine Survivors Network, 2006  
[www.landminesurvivors.org/files/  
ConvHandbook\\_4-30.pdf](http://www.landminesurvivors.org/files/ConvHandbook_4-30.pdf)

EDF Guidance document on the Convention  
on the rights of persons with disabilities,  
European Disability Forum, 2007  
[http://cms.horus.be/files/99909/MediaArchive/  
Top5Campaigns/Microsoft%20Word%20-%20  
Guidance%20document%20UN%20Convention  
-%20EDF%20-%20July%202007.pdf](http://cms.horus.be/files/99909/MediaArchive/Top5Campaigns/Microsoft%20Word%20-%20Guidance%20document%20UN%20Convention-%20EDF%20-%20July%202007.pdf)

*'From Exclusion to Equality' – Handbook for  
Parliamentarians*, OHCHR, 2007  
[http://www.ohchr.org/Documents/Publications/  
trainingI4en.pdf](http://www.ohchr.org/Documents/Publications/trainingI4en.pdf)

*Human Rights. Yes! Action and Advocacy on the  
Rights of Persons with Disabilities*, J Lord et al,  
Mental Disabilities Advocacy Center, 2006  
[http://www1.umn.edu/humanrts/edumat/  
hreduseries/TB6/index2.html](http://www1.umn.edu/humanrts/edumat/hreduseries/TB6/index2.html)

*ICRPD Implementation Toolkit*, Disabled Peoples'  
International, 2006  
[http://www.icrpd.net/implementation/en/  
index.htm](http://www.icrpd.net/implementation/en/index.htm)

*ICRPD Ratification Toolkit*, Disabled Peoples'  
International, 2006  
<http://www.icrpd.net/ratification/en/index.htm>

*Implementation Manual for the United Nations  
Convention on the Rights of Persons with  
Disabilities*, World Network of Users and  
Survivors of Psychiatry 2008  
[http://www.mindfreedom.org/as/act/inter/  
wnusp/un-convention](http://www.mindfreedom.org/as/act/inter/wnusp/un-convention)

*Moving forward: progress in global disability rights  
monitoring*, B Lindqvist, M H Rioux, R M Samson,  
Disability Rights Promotion International, 2007  
[http://www.yorku.ca/drpi/files/MovingForward  
FINAL.pdf](http://www.yorku.ca/drpi/files/MovingForwardFINAL.pdf)

Ratify now (website that supports the global  
grassroots efforts to ratify the Convention on  
the Rights of Persons with Disabilities),  
<http://ratifynow.org/>

*Teaching Kit: International Convention on  
the Rights of People with Disabilities*,  
Handicap International  
[http://www.handicap-international.fr/  
kit-pedagogique/indexen.html](http://www.handicap-international.fr/kit-pedagogique/indexen.html)

## 4 General disability awareness tools/training/manuals/papers

*All things being equal: Perspectives on disability and development*, World Vision, 2001

[http://www.worldvision.org.uk/upload/pdf/Disability\\_paper.pdf](http://www.worldvision.org.uk/upload/pdf/Disability_paper.pdf)

*Disability: A guide to language*, CRIN

[http://www.crin.org/docs/Disability%20\\_language2.doc](http://www.crin.org/docs/Disability%20_language2.doc)

*Disability, Equality and Human Rights: A training manual for development and humanitarian organisations*, Oxfam, 2003

<http://publications.oxfam.org.uk/oxfam/display.asp?K=9780855984854&TAG=&CID=>

*Disability: Promoting the Rights of Children with Disabilities*, UNICEF, 2007

<http://www.unicef-irc.org/publications/pdf/digest13-disability.pdf>

*HIV/AIDS Awareness and Disability Rights Training Manual*, Rehabilitation International, Disabled Organization for Legal Affairs and Social Economic Development and Miracles in Mozambique, 2007

[http://riglobal.org/advocacy/projects/RI\\_HIV-AIDS\\_TRAINING-MANUAL\\_10Dec07\\_FINAL.doc](http://riglobal.org/advocacy/projects/RI_HIV-AIDS_TRAINING-MANUAL_10Dec07_FINAL.doc)

## 5 Resources relating to specific rights of children with disabilities

*CBR: A strategy for rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of people with disabilities*, ILO, 2004

<http://www.ilo.org/public/english/employment/skills/download/jointpaper.pdf>

*Disabilities among Refugees and Conflict-Affected Populations*, Women's Commission for Refugee Women and Children, 2008

[http://www.womenscommission.org/pdf/disab\\_fulll\\_report.pdf](http://www.womenscommission.org/pdf/disab_fulll_report.pdf)

*Disability in Conflict and Emergency Situations: Focus on Tsunami affected areas*

[http://www.ucl.ac.uk/lc-ccr/lccstaff/maria-kett/Behinderung\\_und\\_Dritte\\_Welt.pdf](http://www.ucl.ac.uk/lc-ccr/lccstaff/maria-kett/Behinderung_und_Dritte_Welt.pdf)

*Implementing Inclusive Education: a Commonwealth Guide to implementing Article 24 of the UN Convention on the Rights of People with Disabilities*, R Rieser, Commonwealth Secretariat, London 2008

[www.diseed.org.uk](http://www.diseed.org.uk)

*Index for Inclusion: Developing learning and participation in schools*, Centre for Studies on Inclusive Education

[www.csie.org.uk](http://www.csie.org.uk)

*Making Schools Inclusive: How change can happen*, Save the Children, 2008

<http://www.eenet.org.uk/downloads/Making%20schools%20inclusive%20SCUK.pdf>

*World Report on Violence against Children*, P Pinheiro, UNICEF/WHO/UNHCHR, 2005

<http://www.violencestudy.org/r229>

# Appendix 3: Background to the development of this guide

In producing this guide, Save the Children was committed to ensuring that it was directly informed by the experiences and perspectives of people, including children, with disabilities. The following approach was adopted for its development:

## a) Establishing a technical advisory group

Representatives from disabled people's organisations were invited to join an e-group to advise and comment on drafts, ensure accuracy of the materials, provide illustrations of good practice and identify the necessary scope of this guide. Members of the group were: Kicki Nordstrum, World Blind Union; Helen Schulte, UNICEF; Zuhy Sayeed, Inclusion International; June Waugh, UNICEF NGO sub committee on children with disabilities; Shanta Rau, Rehabilitation International; Khandaker Jahurul Alam: Centre for Services and Information on Disability (CSID), Bangladesh; Dr Nafeesur Rahman: National Forum of Organizations Working with the Disabled (NFOWD), Bangladesh; Rajan Rajiv: Disability Legislation Unit, Chennai, India; Maheshwar Ghimire: Nepal Disabled Human Rights Center.

## b) Preparing an initial outline framework

An outline for this guide was prepared. This indicated the proposed scope and approach to be taken in developing the publication, and was used to gain initial feedback on the ideas being developed.

## c) Regional consultations

Two regional consultations were held in Dhaka, Bangladesh and Sanaa, Yemen. The aim was threefold. First, they provided an opportunity to disseminate awareness and understanding of the CRPD. Second, they were intended as a forum where stakeholders could review the proposed framework for this guide and contribute to its development. Finally, the consultations created an opportunity for forging new partnerships and networks at national and regional levels.

The consultation in Dhaka, in June 2007, was organised jointly by Save the Children and the National Forum of Organisations Working on Disabilities (NFOWD). It involved representatives from Bangladesh, India, Pakistan, Nepal, Afghanistan and Sri Lanka, and provided a rare opportunity for children's rights and disability rights advocates to meet and work together. Too often, children's rights NGOs focus too little on children with disabilities,

and disability rights groups give little attention to children. Accordingly, children with disabilities do not get the attention they need to advocate for their rights. This coming together raised awareness of the potential for future collaboration.

The meeting in Sanaa took place in November 2007. It was organised by the Save the Children country programme in Yemen, in partnership with the Arab Human Rights Foundation. Although the majority of participants were from Yemen, there was also representation from Lebanon, Qatar, Palestine, Jordan, Sudan, Egypt, Austria, Sweden, Nepal and the UK. More than 40 boys and girls participated in the meeting, among them children with all types of disability as well as children without disabilities. In addition, the meeting was attended by the Deputy Minister of Education for Girls' Education, Deputy Minister of Youth and Sports, General Secretary of the Higher Council for Motherhood and Childhood, Executive Director of the Disabled Care and Rehabilitation Fund, representatives of various disabled people's organisations, human rights organisations, national, regional and international organisations dealing with children's issues, representatives of the diplomatic corps and international organisations, academics, activists concerned with the rights of children with disabilities, and experts in relevant fields.

Overall, the outcomes from the two meetings were:

- government commitment in Yemen to review their children's strategy to reflect the obligations on the CRPD
- high level of media interest, including print media as well as radio and television
- heightened awareness of the CRPD, its relevance to the UNCRC and the need to understand both treaties in advocating for the rights of children with disabilities
- partnership-building across child and disability rights organisations
- greater understanding of the experiences of children with disabilities and their capacities for self-advocacy
- information on the tools needed in the field
- illustrative materials and examples of rights violations and good practice
- films recording events and issues that can be useful for advocacy purposes.

#### **d) Preparation of this guide**

Following the consultations, a full draft of the guide was prepared and disseminated to the Technical Advisory Group, as well as to other experts in the field for comments, illustrative material and case studies. A final draft was written, taking into account all the findings from the consultative processes.

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# See Me, Hear Me

A guide to using the UN Convention on the Rights of Persons with Disabilities to promote the rights of children

The UN Convention on the Rights of Persons with Disabilities represents the culmination of years of advocacy by the disability community in their struggle for recognition of their rights. *See Me, Hear Me* is the first book to look at how this Convention can be used to support disabled children, alongside the UN Convention on the Rights of the Child.

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