

ARC resource pack

Study material

Critical issue module 3

Children with disabilities



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When referred to in the text, exercises and handouts are always from the list of training material at the end of the topic where the reference appears, unless the reference specifically points to other topics.

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This module is one of the following series of **ARC resource pack** modules.

Foundation modules

- 1 Understanding childhoods
- 2 Child rights-based approaches
- 3 Programme design
- 4 Participation and inclusion
- 5 Advocacy
- 6 Community mobilisation
- 7 Psychosocial support

Critical issue modules

- 1 Abuse and exploitation
- 2 Education
- 3 Children with disabilities
- 4 Sexual and reproductive health
- 5 Landmine awareness
- 6 Separated children
- 7 Children associated with armed forces or armed groups

All modules include:

- **study material** giving detailed information on the module's subject and a list of further reading
- **slides** giving key learning points and extracts from the study material, offering a useful resource when introducing training events and exercises
- **training material** for participatory workshops that comprises **exercises** giving practical guidance for facilitators and **handouts** for participants.

The following documents are also included in the ARC resource pack CD-ROM to ensure you can make the most of these modules.

- User guide
An introduction to the ARC resource pack and the relationships between modules.
- Training manual
Advice and ideas for training with ARC resource pack materials.
- Facilitator's toolkit
General guidance on how to be an effective facilitator, with step-by-step introductions to a wide range of training methods.
- Definitions of terms
- Acronyms

See **Guidance for training on critical issues** at the end of this document for further help in developing ARC workshops.

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Introduction

Facilitators who have not recently trained or worked in the area covered by this module should read carefully through the various topics, slides, exercises, handouts and readings before starting to plan their training activity. Please note that these materials aim to stimulate learning and discussion, and should be used in conjunction with stated policy (they do not replace it). Trainers are encouraged to adapt the module to their specific geographical or cultural context and to supplement topics with their own or locally relevant material.

Despite international attention and condemnation of discrimination against people with disabilities, including the adoption of the **UN Convention on the rights of persons with disabilities**, discrimination against children with disabilities continues across the world. The underlying attitude of the community towards disability is exacerbated during an emergency. An emergency can often directly or indirectly increase the number of children with disabilities or exacerbate their problems.

This module does not attempt to address all areas that affect children with disabilities in depth but aims to support the development of skills and knowledge in relation to emergency aspects, and to provide information and links for facilitators and trainers who require more detailed resources and guidance.

Structure and content of this module

The circumstances of children with disabilities are not homogeneous and vary in different contexts and cannot be addressed through one approach or model. Although no single model can explain all the factors in the interaction of emergency and disability, there are general guidelines and approaches which should be followed. The understanding of the local context and the resources available will strengthen support to children with disabilities and secure their wellbeing, protection, promotion and fulfilment of their rights. Throughout this module the importance of situation analysis is emphasised; this may need to be repeated or updated in rapidly changing circumstances. The situation analysis should include a risk analysis, with gender analysis as a key component, to ensure girls are not at risk of being invisible.

The table below outlines the structure and content of this module and also provides references to the **Foundation** modules relevant to each topic.

Topic	Subject matter	Relevant Foundation modules
Topic 1	The issue for children	
	Topic 1 explores the basic issues facing children with disabilities, especially since children with disabilities are not a homogenous group. It examines why and how children with disabilities are excluded. Appropriate use of language about disabilities, conceptual frameworks and approaches to disabilities, and humanitarian attitudes, beliefs and practices are laid out.	Understanding childhoods Rights-based approaches Programme design Participation and inclusion Advocacy
	Topic 1 concludes by elaborating risk	



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	factors for children with disabilities in times of instability.	
Topic 2	<p>The law and child rights</p> <p>Topic 2 explains the legal and normative framework supporting work with children and disabilities, including identification of key articles in various international and regional human rights instruments and agreements.</p> <p>Key stakeholders working with disability are identified as complaints or claims mechanisms supporting the rights of people with disability to support the understanding of the rights framework.</p>	<p>Rights-based approaches Advocacy</p>
Topic 3	<p>Assessment and situation analysis</p> <p>Topic 3 examines disabilities and child rights situation analysis, including why using the analysis is important in emergencies.</p> <p>Various elements involved in taking forward an assessment and analysis during planning and implementation are explored.</p>	<p>Programme design Participation and inclusion</p>
Topic 4	<p>Planning and implementation</p> <p>Programme planning and implementation examines the basic programme planning principles and rights-based conceptual frameworks in addressing disability.</p> <p>The importance of the twin-track approach (addressing special needs and treating disability as a cross-cutting issue) is put forth, supported by brief explanations of interventions used in the field. These include community-based rehabilitation, outreach programmes and inclusive education.</p> <p>Advocacy for change examines advocacy strategies to change attitudes of communities as well as the empowerment of people with disabilities organisations and providing an enabling environment for participation.</p>	<p>Understanding childhoods Rights-based approaches Programme design Participation and inclusion Advocacy Community mobilisation Psychosocial support</p> <p>Rights-based approaches Advocacy</p>
Topic 5	<p>Monitoring, evaluation and learning</p> <p>Topic 5 outlines and analyses the current disability programmes to ensure they</p>	<p>Rights-based approaches Programme design</p>



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have the capacity to engage the community and those affected using a rights-based approach to measure both **what** and **how** of the interventions.

Participation and inclusion
Community mobilisation

The dynamic nature of monitoring is highlighted and the range of purposes for ways in which monitoring is used.

This module draws extensively on a number of key documents which should be referred to in full for those requiring a more detailed understanding of children associated with armed forces or armed groups.

Definitions of terms

Adapted mainly from Save the Children, 2009, *See Me, Hear Me* pp4 to 8.

- **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, deaf and blind, 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 fulfill their potential.

- **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 discrimination can be both direct and indirect.
- **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.
- **Person or 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.



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- **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.
- **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.



Topic 1

The issue for children

Key learning points

- Children with disabilities include children 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. The situation is exacerbated in emergencies and children with disabilities face greater vulnerability and discrimination.
- Children with disabilities are not a homogenous population; children with disabilities differ according to culture, gender, ethnicity, age and other factors.
- Why and how children with disabilities are excluded can generally be predicted by looking at the prevailing community attitudes towards disability.
- Appropriate use of language and attitudes toward children with disabilities are important as they can reinforce discrimination against or empower children with disabilities.

The World Health Organisation (WHO) estimates that approximately 10% of the population has some type of disability.¹

The UN Development Programme (UNDP) estimates that 80% of persons with disabilities live in developing countries.²

Disability is an *evolving concept that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others*

Convention on the rights of persons with disabilities, preamble, paragraph (e)

In many cultures, there has been, and in some cultures there still is, a need to rationalise why someone has a disability. Religious or superstitious beliefs have traditionally been relied upon to provide explanations. Such beliefs can at times stigmatise children as outsiders, possessed by spirits or bad karma. This explains to a certain extent why some children with disabilities during both emergency and stable situations are hidden or locked away. Cultural mores have sometimes led to children being killed at birth, or intentionally neglected and left to die.

In countries and societies where children have a significant role in the family economy, children with disabilities may be seen as a burden as they represent a cost rather than a future income. In emergencies, they may even be reproached for surviving the events. The social rejection and exclusion of children with disabilities often results in increased incidence of depression among caregivers and children, which itself may lead to further social isolation and undermines any existing sources of familial resilience.



Children with disabilities are allowed to die ³

A letter sent from an organisation of people with disabilities 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 for whom the death certificate recorded the cause of death as disability.

Children with disabilities face a significantly higher risk of abuse, violence, exploitation and neglect than other children. In emergencies, their situation is likely to be further accentuated and they may be even more prone to harm and their rights abused. Pre-existing abuses, such as social exclusion, are intensified by new rights violations, resulting in increased vulnerability. During war and natural disasters, children with disabilities are more likely to be abandoned, have little access to educational and play opportunities, less mobility and increased risk of death.

Children with disabilities are not a homogenous group

The general use of the term **person with a disability** is often understood as implying a cohesive and homogenous group. **Children with disabilities** consists of a wide variety of identities ranging from the sex of the children to their different ethnicity; ages, and capacities. They may or may not have parents; they may be refugees or living in an institution; they may be rich and well educated or poor and illiterate. They may be resilient children with a capacity for coping, or they may not, just like other children.

Moreover, they might suffer multiple forms of discrimination, not only on the basis of disability but also on the basis of sex, race and other factors. For example, boys and men who have physical disabilities have in most societies higher status than girls. They are more likely to go to school, participate in social and cultural activities, work and marry. In many societies there are more boys with disabilities than girls; they survive longer. In comparison, a girl with a disability is more likely to be abandoned, excluded from education, deemed unsuitable for marriage with few opportunities for motherhood and participation in their society. The point remains that, whether less or more marginalised, both boys and girls with disabilities are often discriminated and excluded from society at large, but the degree of discrimination against girls is higher due to status as a female.

Sterilisation of girls in Australia ⁴

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 to 1997.

Why are children with disabilities excluded?

Children with disabilities are often excluded from activities in society because they are looked upon as **strange, different, or special**. Many people are exposed to various forms of discrimination against persons with disabilities in day-to-day life. But a majority of people have grown up in a segregated society, where they did not have friends, neighbours, partners or colleagues who have disabilities.

Denying the right to family life⁵

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.

In the experience of those who work with children with disabilities, even the very poorest families initially try to care for and protect their child with a disability, but with little knowledge on disability or support to counter negative beliefs or behaviours. Since family members consider a child with a disability as a cost rather than future income producer, the child may be excluded from family decision making, cultural interaction and receive inadequate nutrition or shelter. Children with disabilities may be excluded from even the most basic of rights, such as the right to a family life and to express their opinions in matters that affect them.

In one Save the Children programme in Africa, a visually impaired child was asked to speak about his experience of education with the Save the Children staff. He spoke with confidence, eloquence and very clearly about his abilities, his rights, and his ambitions. Staff members were incredulous; they had never imagined a child with a disability could speak like this. Some even asked whether the child had been coached beforehand. The example demonstrates that even well-meaning people fail to respect the inherent dignity of children with disabilities due to their pre-conditioned prejudices and lack of awareness.

With a lack of information, knowledge, skills, support and resources, the family remains or becomes trapped in a cycle of poverty and exclusion. This is exacerbated during a crisis situation where children with disabilities are often left alone while other family members try to fulfil their needs and access assistance.



Because societies as a whole often lack information and knowledge on the inclusion of children with disability, they become invisible and are forgotten and their social needs are neglected: the child **behind** the disability is seldom seen.

How are children with disabilities excluded?

*'I want to tell them that I am a person like them, that they should ignore my callipers and crutches. All of us are handicapped in some way. The majority of us never have what we want. In my previous class at school there were six other children with disability. We were always at the top of the class. I think it is people's abilities one should focus on, not the things they can't do.'*⁶

Abdelmalik from Morocco

Besides the extreme exclusions, children with disabilities are often denied protection and accessibility to their rights on par with other children in less visible ways. Programmes and policies focusing on street children, refugee children, child labour or sexual exploitation rarely include children with disabilities either implicitly or explicitly. However, as mentioned, children with disabilities will be found in any such groupings.

Although there are various international standards that recognise the rights of children with disabilities, they remain a group that seems largely forgotten or overlooked, and therefore excluded, from general developmental work and emergency aid.

As children with any form of disability have been viewed as needing special care, everything associated with them is consequently viewed as **special**. This view has and still does contribute to increasing their exclusion rather than respecting their rights. This view treats children with disabilities as special and considers that they must have specialists to accommodate them: teachers with special skills and specially trained health staff. This ultimately excludes children with disabilities further because of the preconceived notion of more costs and special human resource.

At times, parents have not been encouraged or allowed to participate and learn about their child's development or to contribute their experiences in specialist interventions. This has left many parents feeling powerless and feeling that they must leave everything to the professionals. The professionals, specially trained in caring for children with special needs have, sometimes, reinforced the thinking that these children need special care at special institutions, special schools, and in special play groups.

Children with disabilities, and their needs, might be special at certain times of their lives but this is the same as for other children; all children are special and have special needs at certain times. However their rights are the same at all times and must be fulfilled, even during emergencies.

Language, conceptual frameworks and approaches

The term handicapped is offensive to many persons with disabilities because it is associated with cap-in-hand and begging. Similarly, the term disabled implies a homogeneous group separate from the rest of society. Children with disabilities are not a homogenous group; they are all individuals. The generally preferred language to use is people or children with disabilities. When in doubt ask the person you are speaking to (see **Handout 1**).

In general terms, approaches to disability can be summarised into four models:



- the charity model
- the medical model
- the social model
- the human-rights model.

These models can overlap and in a society several models can exist simultaneously. However, it is important to reflect on these as a basis for humanitarian and development work.

The **charity model** sees persons with disabilities as victims of their impairment. Their situation is tragic, and they are suffering. Consequently, persons with disabilities **deserve** special support, eg. services and institutions, because they are objects of pity and charity. While persons with disabilities receive benefits under the charity model, they are treated as passive and unable to make decisions on issues that concern them.

In the **medical model** disability **conditions** can be medically diagnosed and treated to a certain extent. Thus, the medical model focuses on the person with a disability as an object of medical treatment, a problem to be fixed so that the person can become **healthier** or as **normal** as other persons in society.

When used in isolation, these models can be seen as an attempt to adapt the person to fit better into society. The implication of these two models is that the person with the disability is seen as the **problem** (she or he cannot see or cannot walk or cannot understand).

In the **social model** the problem is not seen to be the person with the disability, but rather the society in which that person lives. Thus, it is recognised that society does not provide for the needs of persons with disabilities (eg. inaccessible buildings, lack of Braille books, and lack of sign language interpreters). Thus society disables the person by not allowing for her or his inclusion. In the social model the challenge rests with society to remove barriers that prevent adults and children with disability from full and effective participation in society on an equal basis with others. It recognises that a change of attitude in society is necessary and critical if people with disabilities are to achieve equal status.

The **human-rights model** is similar and complementary to the social model but goes further by placing the social model in a legal framework which recognises that adults and children with disabilities must enjoy certain freedoms and have access to certain entitlements and rights on an equal basis with others in order to live a life in dignity. Consequently, the environmental and attitudinal barriers identified under the social model amount to discrimination. The human-rights model requires monitoring of the extent to which freedoms and entitlements are enjoyed without discrimination and requires the State to provide remedies when rights are abused.

These two models stress that society creates and exacerbates disability and society must change its attitude towards adults and children with disability rather than focusing on the particular condition of an individual.

Humanitarian attitudes, beliefs and practices

Current conceptual frameworks, beliefs, attitudes and practice of the humanitarian community can increase or diminish children's vulnerabilities, therefore, governments



and humanitarian organisations working on behalf of and with affected populations need to analyse their approach to adults and children with disabilities.

Until recently, the most common approach to disability was informed by the charity and the medical models. Increasingly this is being replaced by the social and human-rights model, from seeing them as objects of charity to seeing them as individuals with human rights, by removing the physical, linguistic, social and cultural barriers in society. Although much progress has been made, many countries and practitioners still adopt the very narrow medical model, limiting responses to persons with disability in emergency interventions to provision of medical care.

In many cases, surveys and studies undertaken of affected populations, refugees or displaced children, lack information about children with disabilities, and about the challenges faced by their primary caregivers. Statistics usually only state the age and sex of the child, and seldom provide any analysis as to the prevalence or nature of disability. UNHCR's registration forms, for example, only categorise physical disability under their vulnerable groups heading.

In addition, response programmes often unintentionally discriminate against children who did not directly acquire their disability as a result of the war or disaster. For example, rehabilitation facilities may be offered to war casualties or those with disabilities caused by landmines, but they often exclude persons with pre-existing disabilities before the emergency.

The rights of children with disabilities are also overlooked by other service providers and the humanitarian community, for example, those addressing shelter overlook simple accessibility modifications such as ramp access, reachable door handles, accessibility to toilets, adequate light and so on.

Risk factors for children with disabilities in times of instability

After the 1988 floods in Bangladesh an increased number of children with visual disability due to a lack of vitamin A was noticed. This was attributed to a lack of access to fresh vegetables. In the 2005 floods response, food baskets including fast growing green vegetable seeds were distributed to overcome this risk.⁷

Poverty is intrinsically linked with disability. It is both a cause and consequence of disability. Families living in poverty are much more vulnerable to sickness and infection, especially in infancy and early childhood. They are also less likely to receive adequate healthcare or to be able to pay for basic medicines or school fees. The costs of caring for a child with a disability create further hardship for a family, particularly for mothers who are often prevented from working and contributing to family income.

There are several factors that either adversely affect the situation of children and adolescents with disabilities in times of instability, or that actually heighten the risk of disability discrimination. The list below should encourage humanitarian staff to actively explore methods to reduce risk factors, strengthen protection issues, and to adopt a holistic disability rights perspective in their programmes and activities.

- Children with disabilities, including those with sensory, physical, mental or intellectual disabilities, are further vulnerable in emergencies as they will find it more difficult to access standard disaster support services compared to persons without disabilities.



- Children with disabilities might be discriminated against within the household and community and be more invisible than other children, making it harder for emergency services to reach them.
- There is a likelihood of psychological distress amongst children and adolescents with disabilities increasing significantly during conflict, emergencies and/or displacement. The severity of the distress experienced depends on a number of factors such as, the intensity of the exposure to violence (either to themselves or their families), bereavement or loss, as well as the presence of adequate support to assist them during and after the conflict, emergency and/or displacement.
- The exposure to natural disasters, violence and arms may result in large numbers of physical and sensory disabilities such as, amputations, blindness, deafness, and paralysis requiring habilitation and rehabilitation services as well as a range of other specific services and supports in addition to those required for persons without disabilities.
- As a result of an emergency situation, the functioning of basic health facilities and services may be severely disrupted due to reduction of resources for preventative or curative healthcare and even the closure and/or destruction of health facilities.
- There might be a breakdown of traditional community structures and support mechanisms that community members with disabilities normally enjoy, and even lead to the (temporary) loss of normal support and coping methods.
- The separation of children and adolescents from their parents or caregivers often results in deprivation of special care and protection.
- The disruption of the social network related often to displacement or loss of community members results in further isolation of the child and his or her family.
- Children with disabilities are easy targets for abuse and violence; perpetrators could be soldiers or those who are affected by the emergency situation including family members, other children or adults in camps.
- The activities of existing maternal and child health programmes, such as immunisation, may be disrupted or cancelled.
- The level of malnutrition and specific nutritional deficiencies (eg. iodine, vitamins) can result in children and adolescents becoming more susceptible to a variety of infections, such as measles, poliomyelitis and diarrhoeal diseases. A lack of nutrition and of stimulation for infants increases the risk of developmental delay, the effects of which, if prolonged, can be permanent.

For more information on risk and protective factors for children and adolescents in situations of natural disasters, armed conflict and their relationship with trauma and resilience, consult **Foundation module 1** Understanding childhoods and **Foundation module 7** Psychosocial support. See also **Foundation module 4** Participation and inclusion which refers to communicating with children.

Training material for this topic

Exercise 1 The importance of language

Exercise 2 Challenging stereotypes

Handout 1 Language commonly used to describe disability



Handout 2 Myths and stereotypes about people with disabilities



Topic 2

The law and child rights

Key learning points

- In the past two decades a range of legal standards have been developed that provide for the effective protection, development and inclusion of children with disabilities.
- The CRC recognises the economic, social, cultural and civil rights to be enjoyed by all children, including those with disabilities. Consequently, states have specific obligations to ensure that children with disabilities enjoy those rights on an equal basis with others.
- The UN Convention on the rights of persons with disabilities (CRPD) was adopted in 2006. While the CRC establishes the human rights of all children, the CRPD provides a clear focus and detailed elaboration of government obligations and the measures in ensuring that the rights of children with disabilities is protected, promoted and realised.
- By using a rights-based approach, specific obligations are identified for key stakeholders (the State and their representatives, professionals, civil society and parents) who are responsible to respect, protect and fulfil rights of children with disabilities, especially ensuring protection from abuse, neglect and exploitation.

Legal and normative framework

The normative framework regulating the protection, development and inclusion of children with disabilities is captured in various international instruments and national legislation. On the international front, both hard and soft law make up the core regulatory framework. Most importantly, the rights of children with disabilities are explicitly outlined in the CRC and the CRPD. Increasingly national and regional legislation also hold states accountable for respecting, protecting and fulfilling children's rights. Asia, Latin America and the Pacific have adopted specific regional conventions on the rights of persons with disabilities. The Arab states and Africa have also signed declarations related to persons with disabilities. Finally, since the ratification of the CRPD, more and more countries are adopting national policies and legal frameworks to protect children with disabilities.

The Convention on the rights of the child (CRC)

The CRC, adopted in 1989, is the most comprehensive treaty which provides economic, social, cultural, civil and political rights of children and establishes the obligations of the government to protect promote and fulfil the rights of all children. The CRC provides a holistic framework of comprehensive and binding principles which should underpin the treatment of children throughout the world. It establishes a set of universal minimum standards of entitlement for all children.

Many governments have enacted legislation, created mechanisms and put into place a range of creative measures to ensure the protection and realisation of the rights of those under the age of 18. Each government must also report to the Committee on the Rights of the Child for children's rights in their country.

The CRC protects and promotes all children's rights by creating principles and setting standards in healthcare, education, identity, nationality, shelter, right to be brought up



in family environment, participation, play, civil involvement and many other rights. Children with disabilities are often excluded by society and denied their full range of rights on par with other children. Article 23 is dedicated to children with disabilities and reiterates the right of children with disabilities to a full and decent life *in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.*

Article 23

- 1 States parties 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 States parties 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, healthcare 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 States parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive healthcare and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States parties to improve their 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.

Despite this, the scale and severity of human rights abuses against children with disabilities has not been reduced.

The committee recognises 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' organisations and to community-based services and a sustained programme for moving children from institutions to a good family environment.⁸

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.*⁹

For more information on the CRC, see **Foundation module 2** Child rights-based approaches.

The Convention on the rights of persons with disabilities (CRPD)

In 2006, the UN General Assembly adopted the CRPD and its optional protocol. A wide range of stakeholders, including persons with disabilities and their representative organisations, representatives of governments and the UN participated in its development and continue to advocate for universal ratification.

By March 2009, 139 States had signed the convention and 50 had ratified it while 82 States had signed the optional protocol and 29 had ratified it. The CRPD entered into force on 3 May 2008. The convention's text and the current state of ratification can be verified at:

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>

All human rights already apply to all people, irrespective of disability and age. Hence, the intention of the convention was not to introduce 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 realised and obtainable. 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 the convention:

- 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
- establishing 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.

The rights as outlined in the CRPD apply to all persons with disabilities, including children with disabilities. There is also a dedicated article to children with disabilities.

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 realise that right.

The convention is based on the following eight guiding principles:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- non-discrimination
- full and effective participation and inclusion in society
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- equality of opportunity
- accessibility
- equality between men and women
- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The other specific articles that are directly relevant to children with disabilities are as follows.

Specific provisions of the CRPD relevant to children with disabilities ¹⁰

Article	What the convention says
Preamble	Recognises that children with disabilities should have full enjoyment of all human rights on an equal basis with other children.
Article 3 General obligations	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.
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.
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,	Measures must be taken to provide age sensitive assistance to prevent exploitation violence and abuse, age, gender and

violence and abuse	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, thereby prohibiting sterilisation. Children with disabilities have equal rights with respect to family life and governments have obligation 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.

For full text see:

<http://www.un.org./disabilities/documents/convention/convoptprot-e.pdf>

In addition to child-specific provisions, two other articles, *Article 11* and *Article 32*, outline the rights of persons with disabilities in humanitarian contexts.

Article 11 places obligations on states to take 'all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrences of natural disasters.'

Article 32 covers international cooperation and specifies states responsibility to ensure effective cooperation and partnership with the relevant international and local actors, and in particular organisations of persons with disabilities. Specific measures under *Article 32* include:

- ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities
- facilitating and supporting capacity-building, including 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, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

Of relevance to monitoring and evaluation, Article 31 requires State parties to collect appropriate information, including statistical and research data, complying with legal safeguards and respect for human rights norms relevant to the collection and use of statistics, to enable them to formulate and implement policies to give effect to the CRPD.

As with all human rights treaties, monitoring at the national and international level is important. To this end, the convention specifically identifies, at the national level, three mechanisms to assist with the implementation and monitoring of the convention.

- 1 A focal point or focal points within government for matters relating to implementation.
- 2 A coordination mechanism within government to facilitate related action in different sectors and at different levels.
- 3 An ombudsperson or commissioner for children with disabilities within existing framework, such as an independent national human rights commission, to promote, protect and monitor implementation of the convention.

Internationally, the Committee on the Rights of Persons with Disabilities monitors the implementation of the CRPD. In addition to reviewing reports from states on implementation of the convention, the committee also has authority to receive complaints from individuals claiming a breach of any of the provisions of the treaty. The committee may also undertake inquiries when it receives reliable information indicating grave or systematic violations of the CRPD. The individual complaints and inquiry procedures are established under the optional protocol to the convention.

Other important international and regional commitments

In addition to the instruments described above, many other binding and non-binding commitments inform the global regulatory framework on disabilities. This topic provides a list of other significant international and regional conventions and agreements, in each case noting whether they are binding or non-binding.

- The **Universal declaration of human rights** was adopted by the UN in 1948. Although the Universal Declaration recognises the rights of everybody, the rights of persons with disabilities have nevertheless often been ignored and breached over the last 60 years. As a declaration, the UDHR is not, strictly speaking, legally binding on states; however, it is widely accepted as customary international law and therefore binding on all states.
- **Protocol additional to the Geneva conventions of 12 August 1949, and relating to the protection of victims of international armed conflicts** 1977 Specific provisions ensure that all the wounded and sick shall be respected and protected and shall receive, to the fullest extent practicable and with the least possible delay, needed medical care. Binding.
- **1951 Convention relating to the status of refugees** Article 3 is applicable to refugees with disabilities, as it applies to all refugees, including children, without discrimination. Binding.



- **UN Guiding principles on internal displacement** 1998 reflect the concerns of persons with disabilities in Principles 4 and 19. The document includes disability in the non-discrimination clause, and ensures that persons with disabilities *shall receive to the fullest extent practicable and with the least possible delay, the medical care and attention they require*. Non-binding.
- **Ottawa treaty to ban landmines**¹¹ 1997 Article 6.3 states that: *each State party in a position to do so shall provide assistance for the care and rehabilitation, and social and economic reintegration, of mine victims*. Binding.
- **ILO Convention no. 159 Vocational rehabilitation and employment of disabled persons** 1983. Binding.
- **UNESCO Salamanca statement and framework for action: Education for all** 1994 formulated at the World Conference on special needs education. The Salamanca statement on principles, policies and practices in special needs education recognises the principle of inclusion and the need to work towards schools which include everyone, celebrate differences, support learning and respond to individual needs. Non-binding.

Regional instruments

- **The African decade of persons with disabilities** 1999-2009. Non-binding.
- **The Inter-American convention on the elimination of all forms of discrimination against persons with disabilities** 1999. Binding.
- **The Biwako millennium framework for action towards and inclusive, barrier-free and right-based society for persons with disabilities in Asia and the Pacific** 2002. Non-binding.
- **The Asian and Pacific decade of persons with disabilities** 2003-2012. Non-binding.
- **The Arab decade for persons with disabilities** 2004-2013. Non-binding.

Overview of key stakeholders

Duty bearers are those defined as having obligations under the CRC, CRPD and other international human rights treaties. The State is the main duty bearer. It has the obligations to respect, protect and fulfil children rights, including the rights of children with disabilities. It may delegate some of its responsibilities to others, such as private companies and civil society groups. The international community also has obligations to support the State in meeting its responsibilities to fulfil all children's rights. Parents and caregivers are also duty bearers, with specific responsibilities towards children.

The State

By ratifying the CRPD and/or the CRC, States parties have accepted legal obligations to ensure that children with disabilities enjoy their human rights without discrimination.

To illustrate some of the obligations of states in relation to the protection of children with disabilities in emergency situations, consider the following.



The obligation to respect

- In establishing policies and programmes to prepare for or respond to emergencies, the State must not consciously ignore the specific situation of children with disabilities.
- The State has to build accessible physical environments and infrastructure in the future through the use of universal design.

The obligation to protect

- The State must take action to realign traditional and social norms that could hamper the survival of children with disabilities in emergency situations. For example, challenging attitudes that hide children with disabilities which makes it harder to identify them during emergency situations.

The obligation to fulfil

- The State has to collect disaggregated data and statistics on the situation of children with disabilities in order to ensure their adequate protection during emergencies.
- The State has to take steps to dismantle disabling, inaccessible environments which could reduce the capacity of children with disabilities to escape during emergency situations.
- The State must introduce specific emergency services in order to ensure protection and safety of children with disabilities in situations of risk.

As can be seen from the above example, some measures to respect, protect and fulfil the rights of children with disabilities in emergency situations can be introduced immediately, while others might require human and financial resources, as well as time, to implement. For this reason, the CRPD and the CRC include the notion of **progressive realisation**.

Progressive realisation accepts that not all human rights can be achieved overnight such as the economic, cultural and social rights. However, governments are required to take measures to the maximum extent possible within their resources and if needed, by seeking international cooperation. It does not provide for governments to opt out of responsibility in implementing these rights. They have to be able to demonstrate that they have done everything they can through development of strategies, actions and all possible resources for the realisation of economic, social and cultural rights of all children.

CRPD Article 4(2) Progressive realisation

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 realisation of these rights, without prejudice to those obligations contained in the present convention that are immediately applicable according to international law.

In many instances, the additional costs of accommodating the different requirements of a child with a disability are negligible (sitting closer to the teacher when a child has a hearing or visual disability). In others cases, the cost might be avoided through foresight. For example, in considering children with disabilities in planning and design of programmes and policies related to emergency situations, the specific needs of

children with disabilities can be foreseen in advance and the additional costs of adapting policies during or after an emergency can be avoided or reduced. This recalls the principle of universal design.

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.¹² By building an emergency shelter with ramp access in the first place or preparing Braille information on emergency services, the specific requirements of children with disabilities can be foreseen, often at little or no additional cost, and costs avoided at a later date.

It is relevant to note that the greatest obstacle for most children is not the cost of equipment, but the attitudinal challenges and skills transfer to equip professionals with the basics of interacting with children coming from diverse backgrounds. States should give consideration to providing disability equality training to providers of emergency services in order to explain the shift from a medical or charity model to a social human-rights model so that emergency service providers are better equipped to provide for all people affected in a crisis situation.

Other duty bearers

While states have the primary legal obligations to respect, protect and fulfil the rights of children with disabilities, other actors also have responsibilities towards children with disabilities in emergency and non emergency situations. Families, particularly parents, and other caregivers in the community have the responsibility of bringing up children and ensuring their development to their full potential.¹³ In addition, teachers, health workers and social service providers take on responsibility for children, including children with disabilities, in specific situations such as schools and hospitals. Similarly, inter-governmental organisations, development agencies and international civil society organisations have a responsibility to ensure that the rights of children with disabilities are fully integrated and mainstreamed into international development programmes and emergency aid. The private sector might also have responsibilities towards children with disabilities, particularly where the private sector provides essential health, education, social or cultural services. These responsibilities may be moral rather than legal duties.

States can assist these other duty bearers to meet their responsibilities towards children with disabilities in a number of ways. For example, states can promote accessibility audits of training curricula for teachers, health workers or social service providers to ensure that these professionals are sensitised to promote and protect the rights of children with disabilities in their respective fields. Similarly, the State or other actors could undertake an accessibility audit of professionals covering such issues as:

- **attitudes** seeking to find out professional's sense of attitude and responsibility towards children with disabilities
- **understanding of vulnerable situations** to identify and protect children with disabilities in different situations
- **degree of professional expectation** what percentage of time is to be allocated to accommodate the rights of children with disabilities.

Similarly, the State can provide information and knowledge on support services to parents and caregivers of children with disabilities. The presence of a child with a



disability in the family can provide many challenges for families. Information about disability, strategies on coping and knowledge on support services can benefit families and caregivers tremendously. In many countries the state's ability to support services, information and knowledge to families is steadily increasing. This may be disrupted in an emergency setting, but if concrete frameworks are established and information about the rights of children with disabilities are available prior to emergencies, responses to emergencies can be smoother and more sustainable solutions are sought.

Civil society

Many in civil society have a role in bringing about the changes that will be necessary to enable persons with disabilities to enjoy their rights, including special measures for protection from abuse and exploitation. Recent decades have witnessed the growth of organisations of persons with disability, whose input has been critical in the development of the present rights framework. These organisations can provide significant support directly to children with disabilities or their parents, the community and government. They also have an important role to challenge negative attitudes and disseminate awareness on the rights of children with disabilities.

Importantly, representative organisations of persons with disabilities provide a vehicle through which to hear and understand the views and opinions of adults and children with disabilities and can have a crucial role to play in preparing for and dealing with emergency situations. The general obligations of the CRPD require states to consult closely with and actively involve persons with disabilities, including children, in any decisions that affect them, including in the development, implementation and monitoring of legislation and policies Article 4.3.

International agencies

As noted above, international agencies such as UN development and humanitarian agencies, international donor agencies and international civil society organisations have important roles in preparing for and responding to emergencies. In order to meet these responsibilities in a more coordinated manner, UN agencies such as UNICEF, the UN High Commissioner for refugees (UNHCR), the Office of the High Commissioner for human rights (OHCHR), the UN Department for peace keeping operations (DPKO), the UN Mine action service (UNMAS), the World Bank and other agencies with mandates relevant to emergency situations have combined to form an interagency support group for the CRPD. The Interagency support group is committed to coordinating the efforts of UN agencies to strengthen implementation of the convention focusing on joint efforts in the area of policy formulation, programmes, including humanitarian programmes, capacity-building in areas such as training and information sharing, research and access to knowledge and promoting accessibility of facilities, physical environments, information and so on. The Group is co-chaired by OHCHR and the Department of Economic and Social Affairs (DESA). For more information see: <http://www.un.org/disabilities>

Mechanisms in place to support claims

The CRPD and the CRC recognise that children with disabilities have human rights on an equal basis with others with the same freedoms and entitlements as others. If the State does not respect those freedoms and meet those entitlements, persons with disabilities have the right to petition a court, an ombudsman, a national human rights



commission, an administrative tribunal or other mechanism to bring a complaint that their rights have been breached and to request a remedy.

At a practical level, it might be better for children with disabilities and those responsible for them to consider informal mechanisms that are close by in order to resolve a human rights problem. Such informal claims mechanisms might include:

- school based committees or PTAs
- persons with disabilities' committees and organisations
- camp committees.

Actors responsible for planning and responding to emergency situations should consider the most appropriate mechanisms to firstly ensure that rights are respected. Secondly, ensure that the most appropriate and efficient mechanisms are in place which are easily accessible to all, including for children with disabilities in claiming and resolving their grievances in the enjoyment of their freedoms and entitlements.

Training material for this topic

Exercise 1 Understanding needs and rights

Exercise 2 Rights and responsibilities

Exercise 3 Human rights and disability

Handout 1 A framework of children's needs

Handout 2 The CRC

Handout 3 Case study

Handout 4 A child rights ecology

Handout 5 The relationship between the CRC and the Convention on the rights of persons with disabilities (CRPD)



Topic 3

Assessment and situation analysis

Key learning points

- A child rights situation analysis done during an emergency should include an analysis of the situation of children with disabilities.
- Assessment should be holistic in scope, including environmental, attitudinal, cultural and societal factors, not just medical needs.
- Assessment of individuals, even if brief, is important to ensure that reasonable accommodation,¹⁴ including those of protection, of each child with a disability is addressed.
- Children with disabilities and their parents or carers have a right to participate in assessments and should be included in the planning, implementation and analysis of the assessment.

Rational for using child rights situation analysis

Given the numerous risk factors that could either adversely affect the conditions of children and adolescents with disabilities, or increase the prevalence of disability in an affected population, an effective assessment and analysis of their situation is critical to good programming.

In addition to risk mapping, an assessment of the conditions of children with disabilities includes the identification of existing resources and approaches to supporting children with disabilities, and the means by which they may be mobilised. The information provides the opportunity to identify those children or adolescents who require urgent intervention in relation to health and social care in order to prevent the development or deterioration of impairments as well as to start the process of mapping out a strategy to ensure that the rights of children with disabilities are factored into intervention planning.

Making the invisible visible¹⁵

Handicap International experiences highlight that often persons with disability are invisible to the humanitarian community. For example, after the Tsunami in Sri Lanka, humanitarian workers commonly believed that people with disabilities died as they most probably couldn't escape, which proved to be wrong.

In Indonesia after the June 2006 earthquake in Yogyakarta, within two months the joint community team of persons with disabilities organisations and Handicap International identified more than 3,500 persons with disability, 510 who were children with disabilities.

Assessment

In emergencies, it is important to consider disability from the initial phase and to include disability-related questions in rapid assessments, second-phase assessments



and any more comprehensive situation analysis. This can be done by including estimates based on overall numbers when drafting proposals and budgets, and including the identification of adults and children with disabilities in the registration process. Assessments should include information about persons with disabilities as a standard component of general demographic information, such as numbers and profiles of children with disabilities and caregivers.¹⁶

In addition, disability-related questions should be mainstreamed into sector-specific assessments. For example, questions asked during a rapid interagency, multi-sectoral assessment in the Batticaloa IDP camps included questions about whether persons with disabilities had adequate and safe access to drinking water points, wash areas, latrines and whether there were persons with disabilities living alone or without family members and support.

In the displacement of populations related to the conflict in Sri Lanka (August 2006), children highlighted their interest in participating in children's activities in the camps and family members discussed their need for more time to play. Handicap International provided training to Save the Children teams working in child-friendly spaces in IDP camps, which resulted in inclusion of children with disabilities in the programme and allowed family members some space to participate in adults camps activities and family survival activities.¹⁷

In order to examine the extent to which disabilities are affecting children and adolescents, humanitarian staff must tap into the social and cultural understandings of disability. They must identify ways in which the social environment hinders children's access to available services or activities and map potential social, cultural and attitudinal barriers which prevent persons with disabilities from fully participating in community life. Looking at environmental and attitudinal challenges instead of only medical conditions provides critical base line information for good programming and advocacy.

For example, knowing that a girl who has lost a leg has difficulty accessing appropriate support systems or assistive devices is important, but it is equally important to understand if she is participating in regular childhood activities, has access to school and a supportive family life.

Finally, it is important to include assessment information about how children living with disabilities, their families and communities cope with challenges in different settings. Information about what kind of help has been developed locally for children will promote strength based programming and avoid establishing interventions that undermine positive community strategies.

Assessment team composition

From the beginning, children with disabilities and adults and organisations of persons with disabilities should be involved in the planning, implementation, monitoring and analysis of the assessment. Teams that include persons with disabilities are more likely to mitigate bias and to better identify existing resources, services and approaches to children and adolescents with disabilities.



Individual assessments

In addition to assessing the general situation of children with disabilities, it is important to identify and screen for individual cases. Simple questions on disability should become part of screening of all new arrivals in the refugee camp as well as of subsequent data collection or surveys that are undertaken. Appropriate questions can assist to identify functional constraints that may need to be overcome in the planning, for example in relation to additional support to parents, to communication, mobility, safety measures, protection, and the provision of services, schooling and health.

Prompt action in assessing needs *Before action can be taken for treatment and rehabilitation, refugees with disabilities and others who may be at risk must be identified and their needs assessed and analysed against the prevailing environment. When workers are in place before refugees arrive, identification can be done by screening all new arrivals, for those who need immediate assistance and those who should be followed up later.*

Outreach *A combination of house-to-house visits, information from refugee leaders and a selected group of children can be used to identify those who have already settled. In both instances trained refugee community workers can play a major role. This avoids the barriers of culture and language faced by outsiders.*

Medical screening *Some refugees with disabilities will have impairments that are likely to become worse; some may even result in death, if proper medical care is not provided promptly.¹⁸*

During screening, it is important to ask adults, children and youths with disability about their own perception of their needs; how those needs are, or are not met; and, challenges affecting them. Often the priorities and knowledge of facilities of persons with disabilities will differ from the ones perceived by the screening team. The priorities and needs of children with disability are likely to be different to a certain extent to youths with disabilities and adults with disabilities. This also holds true for girls with disability. All these criteria need to be considered during screening.

Challenges

One of the most difficult aspects of carrying out surveys that include persons with disabilities is the issue of definition, and the lack of a standard understanding of the term disability. There are different medically-based definitions such as diagnosis, difficulties in daily living, social and legal definitions. These different definitions come from different viewpoints, use different criteria, and produce different incidence and prevalence rates. However, when looking at the rights of persons with disabilities, the focus moves from defining disability to considering the extent to which an individual experiences discrimination on the basis of disability. Consequently, it becomes less important to define disability and more important to define the factors which cause **discrimination**.

Discrimination could be related to:

- **the physical environment** too many narrow pathways, narrow doorways, steep gradients, staircases
- **attitudes** prevalent beliefs that a child with a disability is less important to tend to during an emergency situation, beliefs that children with disability cannot learn, cannot play with other children for instance



- **information** lack of information in large print, Braille, no sign language interpretation, and so on.

In addition, before undertaking an assessment, it is important to ensure that actors are committed to developing programming and advocacy to address the identified rights violations for children with disabilities. Conducting assessment raises expectations, and it is unethical to undertake an assessment solely for information gathering purposes. As astutely stated by one advocate:

*'Is it a priority to know how many children with deafness there are if we know that there are no means for diagnosing and treating middle ear infection?'*¹⁹

For more information on conducting assessments for disability issues, basic accessibility issues and data collection, see **Handout 1**, Rapid response assessments in camps, **Handout 2** Basic accessibility issues in camps and **Handout 3** Data collection, identification and registration.



Key considerations when planning and conducting assessments

- **Ensure that the assessment is broad and holistic in scope.**

Persons with disabilities often criticise surveys because they focus on the individual aspects of the disability, instead of asking questions about the barriers in the society that actually could be changed. This takes on a narrow, out of date approach that fails to capture the complexity of the issues and hinders identification of appropriate and effective interventions.
- **Take into consideration ethical issues.**

Before undertaking an assessment, it is important to ensure that actors are committed to developing programming and advocacy campaigns to address the identified rights violations experienced by children and adults with disabilities. Conducting assessment raises expectations, and it is unethical to undertake an assessment for solely information gathering purposes. Undertaking awareness and mobilisation exercises may be an essential initial intervention.
- **Advocate with other sectors and child protection workers to mainstream disability issues into standard sectoral assessments.**

Disability issues are rarely included in standard sector assessment tools, nor are they generally incorporated into multi-sectoral tools. Work closely with the cluster system, OCHA, the IASC country team and/or other coordination bodies to mainstream disability questions into demographic and sector sections.
- **Ensure that children and adults with disabilities (with a gender representation) are represented in the assessment and analysis team.**

To minimise bias and improve quality, include persons with disabilities in the planning, implementation and analysis of the assessment.
- **Find ethical ways to identify children with disabilities to ensure their views and experience is reflected in the assessment's finding.**

Even in stable situations, children with disabilities are generally invisible to outside agencies because they are socially excluded, and hidden away from the community. It is important to find appropriate ways to include the invisible in a dignified and ethical way. It should always be remembered that societies may view children with disability in different ways, for example, girls with disability may be more invisible than boys with disability.
- **Adopt an assessment methodology that addresses common communication challenges.**

Working with persons with disabilities often requires special communication techniques. The assessment must include child-friendly tools that also target children with disabilities. For example, drawing can be used to capture deaf children's experience, while creating songs can be used to communicate with blind children. Adequate provision of time will be necessary.
- **Design the assessment to include not only children, but also parents and caregivers as co-right claimants.**

Caregivers face a number of challenges in providing for and supporting their children during an emergency. The State also shoulders obligations to assist and support parents to raise their children in a safe, inclusive and friendly environment.



● **Take into account and build upon existing local initiatives and coping methods towards disability.**

Traditionally, assessments are deficient-based. In order to build more strength-based programme and advocacy responses, it is important to incorporate questions that identify children, families and communities' strengths and assets.²⁰

Analysis

In every country, power, whether political, religious, economic or cultural, is concentrated in the hands of small groups. This can be as a result of tradition, ethnicity, military might or for many other reasons. When small groups hold power they often do so at the expense of others. In an emergency situation, power can be polarised. It leads to those with power exerting more influence to maintain control and access to scarce resources, material and information in the face of chaos. It leads to the disenfranchised and further discriminated of groups who were marginalised before the emergency, being pushed further away from materials and other assets that may determine who lives and who dies.

A rapid child-rights assessment, following the overall principles of a child rights situation analysis (CRSA), is likely to be necessary at the onset of an emergency. This should build on the CRSA and emergency preparedness plans, where they exist. Including children in the assessment process improves data, analysis and support. It also gives access to groups of children for planning and implementation of response. The greater the understanding of the situation, the better planned the response is likely to be.

Although analysis of the assessment information and the various social and environmental factors may sound overwhelming, it is possible to do a rapid analysis based on the rapid assessment and re-evaluate the analysis at a later stage of the response as more comprehensive data is collected. During a rapid assessment the principle of do no harm must come to the front. Preventing the reinforcement of any and all forms of exclusion and discrimination must be taken into account. This is especially true for children with disabilities as they tend to be among the most overlooked and invisible groups.

Following the same principles of holistic assessments, the analysis should be guided by a comprehensive framework that takes into consideration all the complex issues facing children with disabilities and their families.

It can be a useful discipline to utilise the following framework as a way to promote the development of a holistic perspective on the lives of children with disabilities and the realisation of their rights in emergency situations:

- civil and political rights
- family environment and alternative care
- basic health and welfare
- education, leisure and culture
- special protections.



This framework of rights allows for details of each area of children's rights to be examined, which is another aspect of a holistic child rights situation analysis.

As rapid assessments and initial analyses during emergencies tend to be cursory and address immediate survival and protection needs of all, they must be followed up with more comprehensive and detailed ones to ensure the rights and reasonable accommodations of children with disabilities are met.

The team should begin by analysing and documenting the overarching environmental and societal factors. For example, analyse information about available state support to parents (or lack thereof), whether free and compulsory education facilities are available, is there a safe zone where children with disability can play, and whether the health and nutrition services accommodate the rights of children with disabilities. Consider what environmental challenges hinder access to school, medical care and basic support. What is available in terms of resources that can be built upon? If all systems have collapsed, what are their specific needs that must be met alongside the general needs of the population? Framing the analysis in this way will provide the overall context of the situation and shape programming and advocacy efforts to tackle the unpinning societal and environmental factor, not just individual medical needs.

For more information on assessments and situation analysis, see **Foundation module 3** Programme design.

Training material for this topic

- Exercise 1** Nothing about us without us
- Exercise 2** Understanding the barriers
- Handout 1** Rapid response assessments in camps
- Handout 2** Basic accessibility issues in camps
- Handout 3** Data collection, identification and registration



Topic 4 Planning and implementation

Programme planning and implementation

Key learning points

- Every situation is likely to be different, hence specific approaches must be adjusted accordingly.
- Communication with, and participation of, children with disabilities and their parents or caregivers is essential.
- Like all children, children with disabilities are all different individuals with differing needs and desires. They are likely to experience discrimination on multiple levels, hence close cross-sectoral approaches are necessary.
- Education is a basic right and, contrary to common belief, making education inclusive can improve access and quality for all. Attending school provides continuity and creates respect for diversity. It should be a place where children experience values that assist them to take their place in a peaceful, tolerant and just society

CRC Article 29.

Programme planning principles and rights-based conceptual frameworks

After a rapid assessment, often the next step in protecting children and their rights is to develop and implement child-friendly spaces. These are areas where children can gather together under some supervision and may include:

- education
- psychosocial activities
- early childhood development
- cultural and religious activities
- semi-structured play.

It is important that in establishing these areas, children with disabilities are taken into account and a framework of inclusion of all is established.

After the analysis, prioritisation and appropriate programme strategies should be explored. This can be complicated because often it may not be clear who should take responsibility for actions or services for children with disabilities. In situations where the State already has invested in building services, analysis can be undertaken of persons already allocated with responsibility. In other situations where this has yet to happen, the analysis can be the start of a process of determining who should take responsibility and for what.

A capacity gap analysis undertaken with key stakeholders on the rights of persons with disabilities will assist in identifying the key areas of intervention. Please see

Foundation module 3 Programme design.



Handout 3 provides examples of the scope of responsibilities linked to children with disabilities within a school environment. Four basic principles guide all programming and advocacy interventions that aim to support children with disabilities:

- their **best interests** should always be a primary consideration in any decision making that might affect them
- they have a right to be **heard and included**
- their rights should be considered as an inter-related, holistic range of rights ensuring their **survival and development**
- they enjoy these rights **without discrimination**.

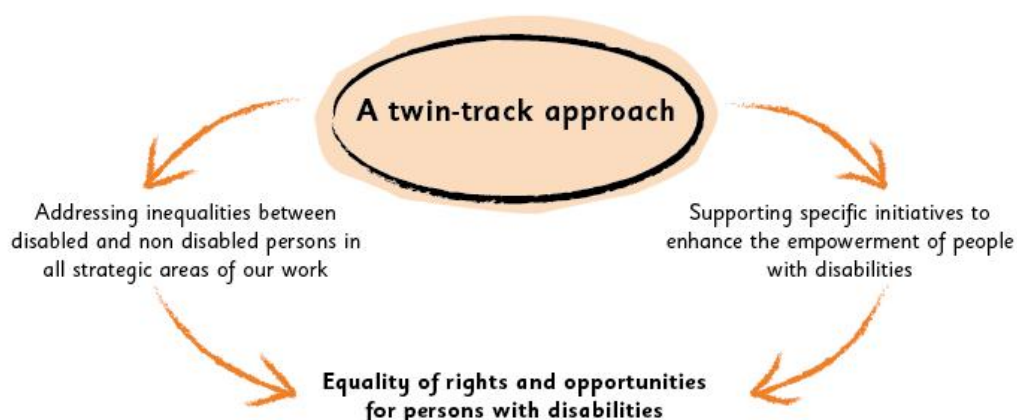
Like all children affected by armed conflict and disaster, children with disabilities have a right to care, protection and psychosocial support. In addition, children with disabilities have specific rights that must be protected, including:

- physical and mental integrity
- access to assistive devices
- familial support for caregivers
- special food and medical care.

Whereas children are commonly excluded from participating in decisions and forums that have an impact on their lives, children with disabilities face an added degree of exclusion because they are often invisible and forgotten. In addition, communication and physical barriers often prevent aid workers from effectively interacting with children with disability (see **Handout 4** and **Handout 5** for tips on effectively communicating with children with disabilities).

Special effort must be made to ensure meaningful children's participation in the development and implementation of programmes, including children with disabilities. While states always remain the primary duty bearer, humanitarian organisations, when assisting the State, or in its absence in filling gaps also have an obligation to develop inclusive programmes that provide equal access to basic services to all children.

Twin-track approach



Twin-track approach to disability and development (DFID, 2000, p4)

Organisations working in the field of disability realise that the provision of concrete services to persons with disabilities is necessary, but stopping there is not sufficient. Rather, it is only the first step in empowering persons with disabilities. The twin-track approach addresses reasonable accommodations (eg. the direct provision of mobility and assistive aids) and treats disability as a cross-cutting issue simultaneously. It aims at mainstreaming disability into every sector and every development and humanitarian action with the overall goal of increasing the general level of awareness and the normalisation of initiatives that include persons with disability as a matter of course.

The social and human-rights models, as introduced in **Topic 1** act as the guiding conceptual framework for developing and implementing rights-based interventions. Based on this model, a number of strategies and concepts for working with children with disabilities have developed. Some of these are described briefly below.

Community-based rehabilitation (CBR)

CBR is a widely used method of working with children with disabilities. It was originally developed by WHO in the 1970s²¹ and involved using available local resources to assist caregivers in the child's local environment to help the child with disability take part in activities where other children were represented.

Today CBR is defined as:

*a strategy within a general community development for the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities.*²²

In general, CBR is implemented through the combined efforts of persons with disabilities themselves, their families, representative organisations and communities, and the relevant governmental and non-governmental organisations. Services include health, education, vocational training, social and other services.

CBR aims to ensure that persons with disabilities are able to maximise their physical and mental abilities, to access regular services and opportunities, and to become active contributors to the community and society at large. It also works to activate communities to promote and protect the human rights of people with disabilities through changes within the community, for example, by removing barriers to participation.

In emergencies, common CRB objectives include:

- identification of children with disability
- putting in place referral mechanisms
- identifying and responding to crucial protection issues.

The CBR concept posits that most problems facing adults and children with disabilities could and should be solved at the community level, with support from national and regional levels. CBR depends on society as a whole taking collective responsibility for members of their community with disabilities. CBR also strives to increase the visibility of children with disabilities in the community as a way to gain greater acceptance.

CBR can be thought of as a low cost strategy, because it is assimilated into society's day-to-day functions. Experience shows that often the development and establishment of a CBR system within a community often triggers other community-based activities, resulting in additional benefits to the community.



Inclusion and inclusive education

Children with disabilities have the same right to have their views heard in decision making that affects them as do their peers without disabilities. They also have rights to information, to associate, to play, to make friends and to learn social interaction skills. They have a right to be a part of what is going on around them, to contribute with their peers.

During situations of conflict, it is necessary to train teachers and community workers and leaders so that they will be sensitive to the rights of children with disabilities, and ensure that they are not marginalised but that their capacities and strengths are positively promoted. Informing parents about their children's rights and needs and working with them to improve services and raise awareness is also a crucial part of the inclusion process.

Inclusion means that whenever there are activities planned for adults and children, consideration about the adults and children with disabilities should be automatic. This is sometimes referred to as the mainstreaming of disability issues.

An inclusive environment is one in which everyone is respected as an individual and where diversity is seen as something that enriches a community's life. Inclusion of children, especially of those with disabilities can be achieved by placing the child or the child's perspective at the centre. Putting children in the centre will make them the focus of the learning process in education or getting children's ideas on how to use space in shelters and physical environment. The child and his or her perspective as the centre of processes recognises the importance of realising the rights of all children.

One of the biggest barriers to inclusion is a negative perception towards children with disabilities. In terms of children with disabilities, access to appropriate education is one of the key ways of supporting their development.

The goal for inclusive education is to strive towards education for all children, which should take place in the same setting, working on the creation of an environment recognising and celebrating the diversity of people by accommodating all children.
The Salamanca statement, 1994

Improving access to education

Inclusive education is an issue that cuts across all education initiatives from early childhood education to primary education, vocational education, adult education, teacher education and curriculum development as well as in spheres related to culture and social development.

Attending school and formalised education in non-school spaces provides continuity and social interaction for all children, with or without disabilities. Children with disabilities have gifts and weaknesses, as do children without disabilities. The role of education should be to try to reinforce the abilities of all children and strengthen and support all children's potential for learning. Equal opportunities mean that children with disability should have an equal right to attend school.

Education is a basic right and, contrary to common belief, making education inclusive can improve access and quality for all, within low resource levels. It is not an expensive luxury. For example, in school, teachers commonly believe that they need specialist skills to teach children with disabilities whereas in practical terms this is not necessarily the case. Learning environments should be accessible in terms of the



physical space, and be considerate of the child's need, for example, being close to the blackboard, or, to have better light by sitting next to a window. These small changes may make the difference between a child with a visual disability getting value from a lesson or being labelled backward and missing out completely. Other children, including those with disabilities, may simply need more time to express themselves, or may need to have a ramp to enter the classroom.

Developing inclusive communication and teaching methods such as using visual cues, clear slow speaking or child participation, will benefit all children. There may be some children who need assistive devices to have full access to education, such as adapted furniture and classroom equipment, and teachers may benefit from support in problem solving, but these are very rarely insurmountable problems.

From exclusion to inclusion in education

So what is meant by the right to inclusive education? Lessons from the experience of Save the Children highlight the following issues.

Inclusive education is part of a strategy for inclusive development; it cannot take place in isolation. The overall goal is to ensure that school is a place where all children participate and are treated equally. This involves a change in thinking about education. Inclusive education is primarily about transforming an education system which responds to the real diversity of children, whether according to disability, ethnicity, gender, age, HIV status or other types of differences. It means enhancing the quality of education by improving the effectiveness of teachers, promoting learning-centred methodologies, developing appropriate textbooks and learning materials and ensuring that schools are safe and healthy for all children. Strengthening links with the community is also vital: relationship between teachers, students, parents and society at large are crucial for developing inclusive learning environments.

Building an education which is inclusive will benefit all children, because it results in school improvement and a methodology and curriculum which is child focused. Inclusive education is more than inclusive schooling; schools are only one part of education which begins in the family and continues throughout life.

Advocacy to promote implementation

Key learning points

- Advocacy for children with disabilities in emergencies can help to strengthen responses and should be built in to programme interventions rather than considering it on its own.
- Children and adults with disabilities can play an important role in advocacy.
- Advocacy with and for children with disabilities should be part of community centred advocacy. Involvement and ownership of communities is essential for its success.

This topic explores the actions that need to be taken to raise awareness of the rights of children with disabilities and promote the recognition and realisation of their rights during (and after) emergencies. It also aims to address the changes required in the policies and institutions which are deterrents to promoting and realising the rights of children with disabilities. It is not an exhaustive list of activities, but rather it sets out



to stimulate ideas and strategies. Prioritisation of activities will depend on the political, social, economic and cultural context.

Significant progress has been made with respect to the rights of people with disabilities in the last two and half decades culminating in the adoption of the CRPD. Although there has been considerable progress in legal recognition, standards and policymaking in relation to disability; understanding, attitudes and positive behaviour changes towards disability is much slower.

The social model of disability, outlined in **Topic 1**, highlights the interaction between persons with disabilities and their environment. To ensure the full and equal participation of children and adolescents with disabilities, one should first assess their social and physical environment and, subsequently, develop strategies to address obstacles or shortcomings in relation to institutions or attitudes.

To change the situation for persons with disabilities, work has to be done on changing negative attitudes and perceptions, and strengthening the positive attitudes and traditions in the society towards adults and children with disabilities. Positive action on disability is an important part of the process by which a community gains more control over its life and more hope about its capacity to solve immediate problems.

Situation of the lives of children with disabilities

It is not possible to begin to address the rights of children with disabilities unless there is a clear understanding of **what** rights are being violated, **why** they are violated and **where**. Undertaking a situation assessment and analysis has been outlined in **Topic 3**. Once an assessment and analysis has been undertaken, it should provide the following information:

- highlight the most important issues
- identify what needs to change and how
- create messages to communicate the need for change and identify where and to whom the message has to be communicated, ie. identifying the targets for advocacy.

While undertaking such assessments it is also important that a thorough assessment is done to identify the partners or possible allies who can help in communicating the message; at the same time it is important to identify possible people or institutions that will resist change.

See **Handout 6** for advocacy ideas for promoting the rights of children with disabilities during emergencies.

Responsibilities of different actors

An analysis of the responsibilities and capacity of various actors (government, local authorities, and other actors) in responding to the needs of children with disabilities in emergencies should help to determine what, and where, are the barriers:

- lack of resources (both financial and human)?
- lack of authority or confusion in who is responsible?
- lack of coordination between different government line ministries and development and aid workers?



- lack of knowledge (cultural and social setting or information on emergency) or how to respond?

Applying the general principles of the CRC and CRPD

Are the general principles of both these conventions understood and complied with by governments, development and aid workers?

Changing attitudes

Changing of attitudes also occurs when people meet each other in a social context. Such interaction can lead to developing better common understanding. If persons with disabilities are part of the society, are visible and speak for their own cause, this will create opportunities for persons without disabilities to change their perceptions. People will get to know the person behind the disability.

Changing attitudes of a society towards disability can only be done over a long period of time, therefore in crisis situation, natural disaster, conflicts or displacement; attitudinal change may not be a priority as such. However, the actions of those responding in emergencies can either serve to reinforce existing prejudices and attitudes, or to provide a positive example to build on later. It is critical to ensure that humanitarian staff are aware of the danger of the invisibility of children with disability and especially of girls with disability and will take appropriate measures to include them in their activities.

Empowerment of organisations of persons with disabilities

Within a model oriented around human rights principles, the real and equal participation of persons with disabilities must be ensured. Persons with disabilities have a right to be heard, to be included, to be informed, and to associate. Especially on the political level this can only happen when persons with disabilities are explicitly provided with the opportunity to speak for themselves.

In the last decades increasing numbers of persons with disabilities have organised themselves, many have built up organisations of persons with disabilities (DPOs) and were the catalyst in the realisation of the CRPD. Working with and supporting DPOs provides people with disabilities opportunities to make their voices heard and contribute to developing relevant programmes.

The mobilisation of persons with disabilities to claim their rights is an important step towards the inclusion of children and adolescents with disabilities. Such organisations have increasingly engaged in defending the rights, needs and priorities of children and adolescents with disabilities.

Organisations of persons with disabilities should be consulted and invited to participate in the planning, implementation and evaluation of services and programmes concerning children and adolescents with disabilities. Their contribution to and involvement in public awareness campaigns is also crucial. Supporting the development of or establishing a coalition involving representation from all types of disability can be an important avenue for coalition building.

Two things are important to point out.



- 1 There is no one-size-fits-all approach. A strategy that works in one community may be completely inappropriate in another. However there is a lot to be learned from studying different strategies, whether they have succeeded or failed.
- 2 Isolated activities for persons with disabilities may have the capacity to support a limited number of individuals, but they will only have a long-lasting impact if they are part of a wider approach eg. as described by the twin-track approach.

Training and capacity building

Assess the capacities of children with disabilities, caregivers and other members of community to claim their rights and how the capacities of those with responsibilities can be built to fulfil their obligations. It is also important to activate social networks to ensure that in already stressed situations children with disability are not becoming an additional burden but that the social network will share the inclusion responsibility.

Even during situations of conflict it is possible to train teachers, and community workers and leaders, so that they will be sensitive to the needs of children with disabilities, and ensure they are not marginalised, and that their capacities and strengths are promoted.

Programmes in which children help each other, as when older children help those who are younger, or in child-to-child programmes focused on understanding other people's feelings and needs, could be used to promote integration of [children with disabilities] (Child-to-child 1993).

Violence and the disabled child Richman N, 1995

The skills of local community workers, whether health or social can be strengthened so that they can participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services. Every effort should be made to provide the opportunity to enable adults and adolescents with disabilities to be part of the community workers team. Trained health advocates could convey important messages and provide information to children and families and help them build support networks. Training and capacity building activities for local organisations involved with disability will also provide the necessary knowledge and resources within the community to ensure the continuity and longer-term sustainability of any activities.

Capacity building of national and local government officials is important. They need to know what their responsibilities are and how to fulfil them with respect to children with disabilities.

The **media** is a critical component on raising awareness on the rights violation and barriers that children with disability encounter on a daily basis during emergencies. They also play an important role in how they portray issues of disability and holding the respective governments to account on their obligations towards children with disabilities. It may be useful to meet with key editors and journalists, offer briefing papers or provide information on the situation of children with disabilities in camps. Involvement in community radio networks might be another avenue of bringing disability issues to the front.



Radio programme in Nepal²³

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 [persons with disabilities] and their rights. Children with disabilities are also invited to express their views on air. It is estimated that the programme reaches up to three 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 [persons with disabilities] 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.

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 countered. One method may be to produce leaflets with simple and accessible messages on the rights of children with disabilities.

Providing an enabling environment

Promoting the inclusion of children with disabilities in regular activities will require more than simply providing assistive devices and equipment, personal assistance, interpreter services and other measures. To achieve the equalisation of opportunities and increase the level of independence for persons with disabilities it will also be necessary to mobilise community involvement in helping to plan, implement and evaluate services. Architects, site planners, construction engineers and others who are professionally involved in the design and construction of the physical environment will need adequate knowledge of disability policy and apply accessibility as basic criteria for their work.

Participation of children with disabilities, their families and caregivers

It is essential that children with disabilities and their families are able to participate in policy and decision-making forums, project design, implementation and evaluation. Organisations of persons with disabilities may provide the most appropriate mechanism by which to ensure this participation.

On a more day-to-day level, parents and other children, and people who work with children in general, have an obligation to try to find ways for children with disabilities to participate in activities within the community. People need to understand that stimulation, play, games, love, and security are as important for children with disabilities as for other children. Even if a child has a physical disability, the community can support the child to develop her or his personal mobility through the removal of environmental barriers and adapting games so the child can participate.

In situations of instability it is not always easy to include children with disabilities in existing programmes, but it is important to do as much as possible, otherwise valuable time will be lost when the child should be learning and developing.

Instable situations can provide opportunities for social change and can be conducive to the introduction of new ways of thinking.



As dreadful as the situation is, it presents an incredible opportunity for social change. Institutions and services have collapsed and people are looking outside for answers. Tuzla is now open to alternative ways of thinking, and disabled people stand to benefit greatly if they can mobilise themselves...Any attempt by disabled people to create a voice for themselves would probably be seen as a threat to the system that has always taken care of disabled people very well.

It seems that it is not only possible to work on social development projects in an unstable society, but also that unstable societies sometimes provide the necessary conditions of shift and change to allow the adoption of new models, such as the social model of disability...with traditional norms breaking down and giving way to progressive alternatives.²⁴

Reporting to the UN Committee on the Rights of the Child

Another way of advocating for and highlighting concerns relating to violation and abuses of rights of children with disabilities is through reporting to the Committee on the Rights of the Child. Findings from needs assessments, situation analysis and monitoring and evaluation can feed into the report.

Reporting to the Committee on the Rights of Persons with Disabilities

Information gathered can also be submitted to the Committee on the Rights of Persons with Disabilities. Information gathered during and post emergencies provide an insight on how children with disabilities are included, how their rights are promoted, protected and fulfilled, and the barriers and solutions in supporting the full development of children with disabilities. The information gathered will identify the strategies needed for future work.

Please refer to **Foundation module 2** Child rights-based approaches and **Foundation module 5** Advocacy for further information.

Training material for this topic

- Exercise 1** Addressing the challenges for a child with a disability in conflict situations
- Exercise 2** Inclusive education
- Exercise 3** Strategies to protect children with disabilities in emergencies
- Handout 1** Case studies
- Handout 2** Case study, and CRC and CRPD articles
- Handout 3** Duty bearer analysis of school environment for child with a disability
- Handout 4** Some tips to remember
- Handout 5** Hints and tips on communicating from young people with disabilities
- Handout 6** Tips to promote the rights of children with disabilities during emergencies



Topic 5

Monitoring, evaluation and learning

Key learning points

- Rights-based monitoring and evaluation should be participatory, culturally appropriate, ethical and monitor fulfilment of rights as well as needs of children with disabilities.
- Successful and useful monitoring and evaluation requires a number of steps to set up a system. These include developing indicators, collecting data, analysing data and using data to improve responses. It is essential to highlight who is responsible for all steps in the process and that this is well managed.
- Data collected at the intervention-level may be used to feed into national-level and international-level monitoring and reporting.

This topic provides guidance on the types of indicators that should be read alongside **Section 5** Monitoring and evaluating efforts to achieve change, which can be found in **Foundation module 3** Programme design and which provides essential information about:

- the different levels of monitoring and evaluation (M&E) that should be considered
- key principles and processes
- guidance around monitoring at national and international levels.

Monitoring involves carrying out activities that help to understand more about the situation, in this case, what is happening to children with disabilities or about activities or programmes and whether they are inclusive of children with disabilities. Specific data is collected and or a range of information related to indicators or programme outcomes with reference to children with disabilities. Enquiries may focus on:

- **the process** for example, how an activity was set up.
- **the content** was the activity seen as useful? Has a positive change been observed as a result of the intervention?

The purpose of all such monitoring activities is twofold: to inform immediate work and to develop learning, either relating to the current situation or other and future programmes.

It is important that programme and activities with children with disability in emergencies is monitored, because children with disabilities, who are normally invisible and disempowered in non-emergency contexts, will be more so in an emergency. The demographics of the overall population should be mapped from the outset, including all the subgroups that comprise the wider population, including children with disabilities and emergency interventions should be implemented accordingly.

The emergency response and interventions should be informed by a combination of the existing child rights situation analysis (if available), emergency preparedness plan and rapid child rights assessment, as well as an internal assessment of human and financial resources. This information will influence and inform the monitoring and evaluation framework. Monitoring and evaluation frameworks must have clearly set



objectives and indicators to measure changes towards discrimination (both positive and negative) against children with disabilities.

Principles of rights-based monitoring and evaluation

A rights-based approach to monitoring and evaluation has implications both for **what** is monitored and evaluated (effort, effect and change, and the standards of the implementation processes used) and **how** monitoring is done.

The monitoring of good process is different to monitoring change and impact; it's an ongoing check on good practice and an issue of management and accountability.

It is also necessary to monitor:

- the extent to which children, adolescent and adults with disability have actively participated in the interventions (and the broader effects of this). Ideally, children with disabilities should be involved in deciding programme interventions, objectives and how effective it has been (monitoring frameworks).
- the degree to which equity has increased and discrimination decreased towards people with disabilities through the interventions.

It is important that there are planned periodic stakeholder meetings or other means of looking at unintended (positive and negative) impacts of programme interventions on children with disability. The time required for planning, monitoring and evaluation may be in tension with traditional ways of working in an emergency, as the process implies the involvement of a range of stakeholders, including children with disabilities. This approach demands systematic planning with stakeholders to respond to immediate survival rights (immediate causes) and longer-term development rights (addressing underlying and root causes, strengthening capacity of civil society and the state).

Save the Children uses an impact assessment framework with five dimensions of change to plan for, monitor and assess the impact and outcome of programme interventions.

- 1 Changes in the lives of children and young people with disabilities.
- 2 Changes in policies and practices affecting children's and young people with disabilities lives.
- 3 Changes in children with disabilities' participation and active citizenship.
- 4 Changes in equity and non-discrimination in the lives of children with disabilities.
- 5 Changes in communities' and civil society's capacity to support the rights of children with disabilities.

Incorporating the principles into monitoring and evaluation

The following table uses the sequence of project logic expressed in a **logical framework** to make a distinction between the different types of indicators that are necessary in order to measure not just outcomes but also the process. This provides a very useful framework within which indicators specific to a programme can be developed.



	Narrative summary	Indicators
Goal fulfilment of children's rights	Which children's rights are being met? (framed as overall changes for children).	What indicators show whether children's rights are being enjoyed?
Objectives contribution to goal	What is the contribution to the goal, framed in terms of resolution of capacity gaps and SMART? ²⁵	What indicators show whether the changes have taken place and how?
Process	How does the process encourage participation, develop capacity, accountability and equity? How does it empower people? How does it affect equity and gender disparity?	What indicators (or other evidence) will be used to measure participation, improved capacity, accountability and empowerment?
Outputs or impact	What outputs or impact will the programme produce that lead to improvements in the fulfilment of rights?	What outputs or impact will be produced and when?
Activities	Have underlying causes been identified and targeted? What activities must duty bearers undertake and when?	Inputs What responsibilities and authorities are accepted and what resources are required by duty bearers over the period?

Getting it right for children: a practitioner's guide to child rights programming
adapted from Save the Children Alliance, 2007 p64

M&E is a dynamic process and mechanisms should be established which ensure learning is fed back into planning and design of future programmes and into an organisation's own institutional learning. If monitoring and evaluation and learning is applied systematically throughout the programme, it will enable continuous review and adaptation. It also provides appropriate information for feedback to children, their carers and communities. The learning can also be used for national and international advocacy. See **Handout 1** for a checklist of monitoring action on non-discrimination in emergencies.

Please refer to **Foundation module 2** Child rights-based approaches, **Foundation module 3** Programme design and **Foundation module 4** Participation and inclusion for further information.

Collecting and disseminating information

Considerable efforts may be required in order to upgrade or establish a statistical information system on disability, especially in emergency or displacement situations. It requires the adoption of a disability perspective in the assessments from the early stages of an emergency. Questions on disability should become part of screening, and subsequent data collection or surveys of all new arrivals in refugee or IDP camps or other areas for displaced people. In this process persons with disabilities themselves should be involved in order to set up priorities. Information on the types (not seen as

a diagnostic but as broad categories) of disability, the extent to which that disability affects the population, and the available services and coping mechanisms within or outside the camp should be gathered and processed.

At the same time information related to the environment and its barriers should be highlighted as often very simple measures may completely change the visibility of children with disability.

This information should be used to inform not only programming decisions but public information and education campaigns aiming to raise awareness of the rights, obligations and capacities of persons with disabilities. Negative attitudes can be influenced through information and increased knowledge about what disability is and why it happens. Persons with disabilities are potentially their own most influential advocates; their own perception of themselves will be transmitted to others.

Training material for this topic

- Exercise 1** What change for children?
- Handout 1** How to measure change
- Handout 2** Case study
- Handout 3** Questions
- Handout 4** Table of issues and changes required



Endnotes

- 1 *Some facts about persons with disabilities*
<http://www.un.org/disabilities/convention/facts.shtml>
- 2 Ibid.
- 3 Gambian association of deaf and hard of hearing, 1999, as cited in
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, 2009 p87
- 4 Disability Awareness in Action human rights violations database as cited in
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, 2009 p98
- 5 *What works? Promoting the rights of children with disabilities: guidelines for action*
Lansdown G, Disability Awareness in Action, London 2003 as cited in
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, 2009 p93
- 6 From *In our own words*, Save the Children Fund UK
- 7 <http://www.handicap-international.org.uk>
- 8 Report of the Committee on the Rights of the Child to the former Commission on Human Rights sub-commission on prevention of discrimination and protection of minorities in February 1996
- 9 Ibid.
- 10 *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, 2009 pp 26-27
- 11 Formally known as 1997 Convention on the prohibition on the use, stockpiling, production and transfer of anti-personnel mines and on their destruction
- 12 CRPD Article 2
- 13 CRC Article 18
- 14 **Reasonable accommodation** is a term used in the Convention on the rights of persons with disabilities that means the following: *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.*
- 15 <http://www.handicap-international.org>
- 16 Ibid.
- 17 <http://www.handicapinternational.be/en>
- 18 *Community services guidelines: assisting disabled refugees* UNHCR, 1996 p32
- 19 *Disabled children in developing countries* Zinkin P
- 20 This table is adapted from a UNICEF document.
- 21 As of September 2009, new CBR training guidelines are being developed by the UN, including a specific chapter on CBR in conflict.



Endnotes

- 22 Joint position paper on CBR published in November 2004 (WHO, UNESCO and ILO).
- 23 *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, 2009 p59
- 24 *Disabled children in a society at war: a casebook from Bosnia* Hastie R, Oxfam, 1997
- 25 SMART is an acronym often used to describe the characteristics of a good objective, which must be specific, measurable, achievable, realistic and timebound.



Further reading

- *All things being equal: perspectives on disability and development* World Vision, 2001
- *A matter of social context: the sexual abuse of children with disabilities* Berglund A, Rädda Barnen, Stockholm 1997
- *Community services guidelines on assisting disabled refugees: a community-based approach* UNHCR, 1996
- *Disabilities among refugees and conflict affected populations: resource kit for field workers* Women's commission for refugee women and children, 2008
- *Disability, liberation and development* Coleridge P, OXFAM, UK 1993
- *Disability: promoting the rights of children with disabilities* UNICEF, 2007 <http://www.unicef-irc.org/publications/pdf/digest13-disability.pdf>
- *Disabled children and developing countries* Zinkin, McConachie, Mittler, McKeith Press, 1995
- *Disabled children in a society at war* Hastie R, OXFAM, UK 1997
- *Focus on refugee children, a handbook for training field refugee workers in social and community work* Save the Children Sweden, Stockholm 2000
- *Gender and disability: women's experiences in the Middle East* Abu-Habib L, OXFAM, UK 1997
- *How to include disability in disaster management* Handicap International, Bangladesh May 2006
- *International classification of impairments, disabilities and handicaps second edition (ICIDH-2)* World Health Organisation, Geneva
- *Inventory of documentation about children with disability in armed conflict and displacement* Åhlen E, Rädda Barnen, Stockholm 1997
- *Making reality of the rights of the child* Hammarberg T, Rädda Barnen, Stockholm 1996
- *Making schools inclusive: how change can happen* Save the Children, 2008
- *Non-discrimination in emergencies: training manual and toolkit* Save the Children, New Delhi 2008
- *Promoting psychosocial wellbeing among children affected by armed conflict and displacement* Save the Children Alliance, 1996
- *Salamanca statement and framework for action on special needs education* UNESCO, 1994
- *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, London 2009
- *Standard rules on the equalisation of opportunities for persons with disabilities* UN, New York 1994



Further reading

- *UN Convention on the rights of persons with disabilities* United Nations, New York 2007

Websites

- CRIN
(Homepage of Child Rights Information Network and has a dedicated thematic area on children with disabilities.)
<http://www.crin.org>
- DAA
(Homepage of Disability Awareness in Action.)
<http://www.daa.org.uk>
- Handicap International
(Homepage of Handicap International.)
<http://www.handicap-international.org.uk>
- International Labour Organisation (ILO)
(Homepage of the ILO's disability and work.)
<http://www.ilo.org/public/english/employment/skills/targets/disability/index.htm>
- OXFAM
(This address links you directly to OXFAM publications and can be used for ordering the three publications listed in the further reading section.)
<http://www.oxfam.org.uk/>
- Save the Children Sweden
(This is the homepage of Save the Children Sweden's child rights bookshop and can be used for ordering their publications.)
<http://www.childrightsbookshop.org>
- UN
(Key documents on disability.)
<http://www.un.org/disabilities/default.asp?id=182>
- UN Enable rights and dignity for persons with disabilities
(Primary UN source of information on disability.)
<http://www.un.org/disabilities/index.asp>
- UNESCO
(General information on special needs education including the text of the Salamanca statement.)
http://www.unesco.org/education/pdf/SALAMA_E.PDF
- World Health Organisation (WHO)
(The homepage of the International classification of impairments, disabilities and handicaps. ICIDH-2 can be viewed at this site.)
<http://www.who.int/en>
- World Health Organisation's Child Health and Development (CHD) website
<http://www.who.int/en/>
- Young voices on the UN Convention on the rights and dignity of persons with disability
<http://youngvoices.leonardcheshire.org/wp-content/uploads/2013/09/Young-Voices-report-2005.pdf>



Guidance for training on critical issues

All Critical issue modules follow the same pattern of five topics.

- **Topic 1** The issue for children
- **Topic 2** The law and child rights
- **Topic 3** Assessment and situation analysis
- **Topic 4** Planning and implementation
- **Topic 5** Monitoring, evaluation and learning

Anyone facilitating a training or awareness-raising event on a specific critical issue should refer to the recommended **key learning objectives** below for each of these topics. With each of the sets of learning objectives is a suggested **sequence of information** to be followed when tackling the topic, in order to ensure that the learning objectives are achieved.

Topic 1 The issue for children

Key learning objectives that participants should be able to:

- describe why and how this critical issue impacts on the lives and rights of children in humanitarian settings
- be motivated to address these issues effectively.

Sequence of information

- 1** What this critical issue covers (might include definitions, different situations, manifestations, interpretations).
- 2** How it impacts on children (at different ages and stages; in different situations; considerations of gender and exclusion).
- 3** Why it is important to respond.

Topic 2 The law and child rights

Key learning objectives that participants should be able to:

- cite and justify relevant legal instruments and standards in relation to this critical issue
- identify key duty bearers in relation to the issues addressed in this module
- cite and respect key guiding principles in addressing these issues.

Sequence of information

- 1** Relevant legal instruments and standards.
- 2** Relationship between duty bearers and rights holders.
- 3** Guiding principles.



Topic 3 Assessment and situation analysis

Key learning objectives that participants should be able to:

- describe why rights-based assessment and analysis are essential components of any programming in humanitarian environments
- develop a plan and process for assessment and/or analysis that is informed by rights-based principles and approaches; and which addresses the specific issues raised in a particular module
- identify challenges that they may face.

Sequence of information

- 1 Why assessment and analysis is essential
- 2 Difference between assessment and analysis and where each is appropriate
- 3 Core principles
- 4 Key tools
- 5 Challenges and opportunities
- 6 Plan for assessment and/or analysis

Topic 4 Planning and implementation

Key learning objectives that participants should be able to:

- describe principles and approaches that should be part of any and all implementation strategies
- reflect on how these approaches should apply to the different implementation strategies that address the issues raised in a situation analysis
- make informed decisions about which of these strategies to prioritise and how to implement them effectively.

Sequence of information

- 1 Relevant guiding principles:
Working to common goals
Coordinated approach
Participation and inclusion.
- 2 Prevention and implementation strategies:
The three pillars
Monitoring and reporting on progress in achieving children's rights.
- 3 Prioritisation and operational guidance



Topic 5 Monitoring, evaluation and learning

Key learning objectives that participants should be able to:

- describe overall (dimensions of) change to which all child rights-based programmes are working
- describe how interventions proposed in relation to this critical issue contribute to this process of change
- develop relevant indicators of progress at output and outcome levels
- use participatory and inclusive approaches in gathering and analysing indicators.

Sequence of information

- 1** Overview of dimensions of change to which all child rights-based programmes are working.
- 2** Clarity about relationship between impact, evaluation and monitoring processes and indicators required at each level.
- 3** Development of sample indicators for each level.
- 4** Guidance about appropriate and inclusive methodologies for M&E.

Links to Foundation modules

It is important to refer to relevant Foundation modules when gathering information to support activities in relation to individual topics. The links between Critical issue topics and Foundation modules are outlined below.

- **Topic 1** The issue for children
Foundation module 1 Understanding childhoods
- **Topic 2** The law and child rights
Foundation module 2 Child rights-based approaches
Foundation module 5 Advocacy
- **Topic 3** Assessment and situation analysis
Foundation module 3 Programme design
Foundation module 4 Participation and inclusion
- **Topic 4** Planning and implementation
Foundation module 4 Participation and inclusion
Foundation module 5 Advocacy
Foundation module 6 Community mobilisation
Foundation module 7 Psychosocial support
- **Topic 5** Monitoring, evaluation and learning
Foundation module 2 Child rights-based approaches
Foundation module 3 Programme design

For further guidance on developing and running training and awareness-raising events please refer to the **Training manual** and **Facilitator's toolkit** on the ARC resource pack CD-ROM.



Planning guide

Ideally anyone facilitating a training or awareness-raising event should work with a small planning group of resource people who have a good understanding of the local area and the targeted training group. They need to ensure that:

- they agree the best possible capacity-building intervention with the commissioning manager for the event
- they make rights **real** in any workshop, for example by building in field visits, showing relevant videos and DVDs, encouraging personal reflections and developing a workshop **bill of rights** with the participants
- they emphasise participation, inclusion and accountability at all stages.

The table below can be used when considering how best to present or enable participants to achieve the **key learning objectives** of each topic covered.

Sequence of information	Methodology eg. exercises, discussions	Comments eg. specific target groups

