Critical Issues

Disability

CONTENTS

BRIEFING NOTES FOR FACILITATORS **Page**

TRAINING MATERIALS

RESOURCES

Disability

Introduction

Facilitators who have not recently trained or worked in the area covered by this Resource Pack, should read carefully through the various Topics, Overheads, Exercises, and Handouts 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).

INTRODUCTION

Disability is part of human life, and children with disabilities can be found in every society, every culture and every community throughout the world. They have the right to respect and support in order to ensure their full participation and equality in society, but often, as a result of social attitudes or environment, are they unable to realise these rights.

According to the 1996 United Nations *Study of the Impact of Armed Conflict on Children*, armed conflicts in the previous decade had caused over a million deaths of children in poor countries. And for each dead child, three more had been injured or physically disabled and many more psychologically damaged. The needs of children with disabilities are basically the same as those of other children, but in situations of conflict and displacement it becomes more difficult to ensure that these needs are met.

Children with disability are seldom included in overall development programmes, even less so in situations of armed conflict and displacement. Therefore it is important that organisations, working with emergency assistance and developmental programmes, discuss and exchange experience about how to promote the rights of children with disability.

KEY CONCEPTS

1. Disability is part of human life, and children with disabilities can be found in every society, every culture and every community throughout the world.

2. Attitudes towards people with disabilities vary among different cultures and religions, likewise the notion of what is meant by disability. These prevailing attitudes dictate the level to which children with disabilities are included or excluded from society.

3. The needs of children with disabilities are basically the same as those of other children, but in situations of conflict and displacement it becomes more difficult to ensure that these needs are met.

4. Children with disabilities enjoy equal rights with all other children.

5. Analysis of the individual/medical and social models of disability can be useful in understanding underlying attitudes, and in informing effective approaches.

6. Guiding principles of any approach should be sound communication and participation.

7. Excluding children from activities prevents access to the very support they need for their development.

8. There are a number of ways of encouraging changes of attitudes towards disability and promoting inclusion.

Note: This resource pack does not aim to provide special knowledge about the different types of disability and medical/paramedical treatment, but rather concentrates on the social aspects of disability. There are many manuals and other sources of information dealing with the medical aspects of disability that facilitators can refer if they need this type of information. However, **Disability Reading 1.1** does provide some information about the most common types of disability.

Training on issues of disability is often more effective if it occurs alongside training in other topic areas because children with disabilities can be found in any group of children and in any situation.

OVERVIEW AND DEFINITIONS

This Resource Pack demonstrates how prevailing social and individual attitudes towards disability largely dictate the level of inclusion (or exclusion) of children with disabilities within society. It also gives humanitarian staff the opportunity to explore and review their personal beliefs and attitudes towards disability.

An overview is provided of the international legal framework concerning children and adults with disabilities, and several strategies for encouraging positive changes to attitudes and promoting inclusion are presented. Particular focus is placed on inclusive education.

Definitions are central to understanding people's starting points and attitudes towards disability. Take the term disabled, for example: does this mean that the child's condition is disabling, or rather that society's attitudes towards that child "disable" the child?

Different definitions of disability are covered in **Topic 1**.

Children with disabilities will be found in any situation where there are refugees or internally displaced persons. The challenge is to work towards their inclusion in society whether through: working to change attitudes so that the child is valued and included in school and in other social arenas; looking to improve physical access to services; or ensuring that a disability perspective is included in all programming issues. Lack of awareness may mean that, unless children with disabilities are specifically mentioned in policies, project design and implementation, monitoring and reporting, evaluation and training, they will stay marginalised within the general children's agenda.

THE IMPORTANCE OF THE CRC

The CRC provides the most comprehensive framework for the responsibilities of States parties to all children within their borders: by ratifying the Convention, national governments have committed themselves to protecting and ensuring the rights of all children without discrimination, including the rights of children with disabilities, and refugee and displaced children and adolescents.

The approach of the Convention is holistic, which means that the rights are indivisible and interrelated, and that all articles are equally important and all apply equally to all children.

Of particular significance in relation to children with disabilities is Article 23 of the CRC, which stipulates that these children have the right to special care, education and training that is appropriate to their and their caregivers' condition. This article emphasises the need for all programmes, directly or indirectly targeting children, to take account of the issue of disability. However, it must be read alongside all other articles, as a mere focus on the special condition and special needs of children with disabilities could result in their further isolation within society. Article 23 also promotes the right of children with disabilities to full participation in society and to equality of opportunities.

STRUCTURE OF THIS RESOURCE PACK

This Resource Pack is presented under the following six **Topic** headings:

Topic 1: explores different attitudes towards girls and boys with disability, and looks at how these attitudes affect the way that these children are perceived and treated. It also outlines the different internationally accepted definitions for the terms disability and impairment.

Topic 2: looks specifically at the situation for girls and boys with disabilities in situations of armed conflict and displacement.

Topic 3: provides an overview of relevant and useful legislation regarding the promotion of rights for children with disabilities.

Topic 4: introduces two different models of disability: the individual/medical model, where the disabling 'condition' can be medically diagnosed and treated, and the social model where the 'problem' is seen rather as the society in which that person lives.

Topic 5: investigates how, where and why children with disabilities are excluded from participating in many situations that would be beneficial to them.

Topic 6: provides ideas and methods for how children with disabilities could be included in general terms, and specifically with regard to education. Suggestions for encouraging the active participation of these children are also included.

Participatory exercises, case studies, overheads and handouts are provided. Facilitators are strongly recommended to develop regionally or country-specific materials such as case studies, in order to make the training material more relevant.

Disability
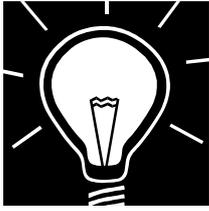
Topic 1
Disability – Attitudes and Definitions

KEY LEARNING POINTS

- *Prevailing attitudes towards disability largely dictate how excluded a child with disabilities will become within his or her society.*

- *We need to acknowledge and understand our own attitudes towards disability before setting out to work with this issue.*

- *The term disability is not a universal concept and varies according to culture, gender, individual and prevailing attitudes within society(ies).*

Disability is part of human life, and children with disabilities can be found in every society, every culture and every community throughout the world. They have the right to respect and support in order to ensure their full participation and equality in society.

The Resource Pack challenges the popular view of disability as simply an individual phenomenon, which can be medically diagnosed. Instead of this individual/medical approach, it promotes a social approach to disability, which highlights the interaction between persons with disabilities and the environment. It demonstrates how prevailing social and individual attitudes towards disability largely dictate the level of inclusion (or exclusion) of children with disabilities within society. It also gives staff the opportunity to explore their personal beliefs and attitudes towards disability.

ATTITUDES TOWARDS DISABILITY

Attitudes towards people with disabilities vary among different cultures and religions, likewise the notion of what is meant by disability. In simplistic terms, disability can be defined as a kind of impairment that makes it difficult for the person concerned to do what other people are able to do. Disabled people may have impaired speech, hearing or vision, or find it difficult to learn or to move about. Some may behave strangely, or have fits or seizures.

However, a form of impairment that is regarded as a disability in one culture may not necessarily be so in another. Just how disabling an impairment may be is determined by the attitude of the surrounding community. Superstitions, myths, religious notions and lack of understanding determine people's attitudes towards disability. This applies equally to governments, institutions, NGOs, teachers, parents and, not least, ourselves. Thus, in many cultures, girls and boys with disabilities find that their human dignity is impaired: not only do they have to struggle with their own disabilities, but they also have less opportunities for

individual development. They risk being hidden away, as though they were some kind of inferior human being. They also risk being oppressed, abused and exploited. In some cultures, having a disabled child may be regarded as shameful or as a punishment from God. There may even be a belief that disability can affect anyone who touches the person who has it.

Children who are kept away from other children and from society as a whole have, quite simply, fewer opportunities to learn and develop. And a society that does not see or interact with girls and boys with disabilities will never have an opportunity to challenge its own prejudices and to move towards a better understanding of the child, or children, "behind the disabilities".

By first and foremost seeing the girl/boy *behind* the disability we can meet them with respect.

> In Northern Mali, the most disabling condition for a woman is to be ugly. This condition is defined in very clear terms. These women do not get married and consequently do not fulfil their normal parental role. If a man marries an ugly woman, it is commonly believed that the duration of his life will shorten by one day for each day of marriage.
>
> In other countries, dwarfs, people missing an ear or an eye, a toe or a finger may have no functional limitations and yet labelled "disabled".

EXAMINING OUR OWN ATTITUDES

In setting out to work to assist children with disabilities and their families, it is important to be aware of the kind of ideas and pre-conceived notions about disability that prevail in that local community and to work, with respect for those attitudes (even if we do not agree with them). But the step before that is to understand and acknowledge our own attitudes towards the issue of disability. We all carry round with us pre-conceived notions and attitudes which are not necessarily grounded in fact, and which we therefore need to reconsider before starting to work on these issues. The training materials for this **Topic 1** provide methods for exploring our own attitudes.

DEFINITIONS

It will always be impossible to define the precise number of children with disabilities in the world because the concepts of both 'impairment' and 'disability' are defined differently according to different cultures and contexts. There are many different types of impairments both visible and invisible. The extent to which children with impairments are disabled depends on many factors, such as the attitude and behaviour of others towards them (parents, teachers, neighbours), whether or not their basic needs are being met, policies which include or exclude them, the accessibility of the environment, their access to appropriate basic support for their development.

In May 2001, the 54th World Health Assembly endorsed the World Health Organisation's (WHO) second edition of the International Classification of Impairments, Disabilities and Handicaps (ICIDH-2), giving it a new title, the

International Classification of Functioning, Disabilities and Health.

The aim of the ICIDH-2 classification is to provide a unified and standard language and framework for the description of human functioning and disability as an important component of health. The term 'handicap' has been abandoned and 'disability' used as an umbrella term for impairments, activity limitations or participation restrictions associated with health. 'Activity Limitation' replaces the term 'disability' used in the 1980 version of ICIDH and 'Participation Restriction' replaces the term 'handicap'.

ICIDH-2 also lists environmental factors that interact at the body, individual or society levels and in this way provides a useful profile of individuals' functioning, disability and health in various domains.

ICIDH-2 has two *part*s, each with two *components:*

Part 1: Functioning and Disability

> (a) Body Functions and Structures

> (b) Activities and Participation

Part 2: Contextual Factors

> (a) Environmental Factors

> (b) Personal Factors

The body of the text provides various definitions for terms used, including the following.

Functioning refers to all body functions, activities and participation as an umbrella term.

Disability serves as an umbrella term for impairments, activity limitations or participation restrictions.

Body functions are the physiological functions of body systems (including psychological functions).

Body structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations.

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

Handout 1.2 reproduces Appendix 1 of the ICIDH-2, which provides more detailed notes on various terms used within the document.

Please note: at the time of writing the second edition of the International Classification of Functioning, Disability and Health (ICIDH-2) is in final draft form. This document and further information can be found on the internet from the World Health Organisation at: http://www.who.int/icidh.

The ICIDH-2 has been accepted as one of the UN social classifications and is referred to in and incorporates the **UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities** which describes disability thus:

Disability: "*summarises a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature*".

Dr. Einar Helander states in his book 'Prejudice and Dignity' that there are many complexities related to disability definitions. The simplest and maybe the initial definition of a disabled person appears according to Helander:

"a person who in his/her society is regarded as disabled, because of a difference in appearance and behaviour".

The three sets of definitions above are presented as Overheads 1.3, 1.4 and 1.5.

In summary, the concept of disability itself must not be taken for granted. In many cultures, one cannot be 'disabled' for the simple reason that 'disability' as a category does not exist. There are blind people and 'slow' people, but 'the disabled' as a general term does not translate easily into many languages. For example, the Maasai term used to translate the English word 'disabled' actually refers to a lizard that walks in an awkward way.

TRAINING MATERIALS FOR TOPIC 1

Overhead 1.1: Key Learning Points for Topic 1	Summary of key learning points
Overhead 1.2: Disability is a Major Feature of Life	Quotation
Overhead 1.3: WHO - Definitions	Definition
Overhead 1.4: UN Standard Rules - Definition of Disability	Definition
Overhead 1.5: Definition of Disability from "Prejudice and Dignity" Dr Einar Helander	Definition
Exercise 1.1: Exploring Attitudes Towards Disability	Uses different statements about disability to encourage participants to examine their own attitudes towards disability.
Exercise 1.2: Exploring Attitudes Towards Disability: Relational Attitude Scale	Small group work where participants work through a questionnaire and examine their own attitudes towards disability
Exercise 1.3: What Does "Disability" Mean?	Participatory exercise where participants share ideas to produce their own agreed definition of "disability".
Exercise 1.4: Who is Disabled?	Exercise using a number of questions or situations to pose questions about what is disabling in this situation?"

Handout 1.1: Children learn from Their Experience of Adults	Short thought provoking handout
Handout 1.2: Terms for categories in ICIDH-2	More detailed definitions of terms
Handout 1.3: An Overview of ICFDH-2	
Reading 1.1: Some of the More Prevalent Illnesses Which Result in Disability	Detailed background information on the subject.

FURTHER SUGGESTIONS FOR TRAINING

Ask participants to read through the different definitions of disability presented in Disability Overheads 1.3 and 1.4, and to discuss the possible attitudes underlying these definitions. Then show them Disability Overhead 1.5 and discuss how this is different.

Ask participants to discuss in small groups who they consider to be disabled in their own culture(s). Which groups are excluded? Denied rights? Discriminated against?

Disability
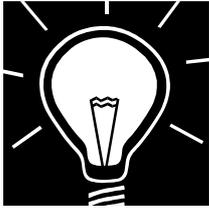
Topic 2

Girls and Boys with Disability: Their Situation in Armed Conflict and Displacement

---

KEY LEARNING POINTS

- *In extreme situations, such as war, flight from war, or displacement, the plight of children with disabilities becomes much harder.*

- *The needs of children with disabilities are basically the same as those of other children, but in situations of conflict and displacement it becomes more difficult to ensure that these needs are met.*

- *One of the results of conflict situations is an increase in the number of boys and girls with physical or mental impairments.*

- *The situation of children with disabilities in times of conflict needs to be explored further. There needs to be more knowledge about how they, their families and their communities cope with disability in different settings.*

In difficult or extreme situations - in war, during flight, during displacement, or where hunger and disease are rife - the plight of children with disabilities becomes much harder. Children with disabilities are less likely to escape during an attack, especially if they have a motor or learning difficulty, or for other reasons cannot look after themselves. Parents may have to make agonising decisions as they flee about how many children, and which children, they can manage to protect. At the same time, in these extreme situations children run the greatest risk of becoming sick or injured, which may lead to disabilities. There are also likely to be increased risks of birth complications or being disabled for life as a result of untreated disease or malnutrition. Negative attitudes towards disability in such situations can have dire consequences.

Additionally, children with disabilities are often "hidden" away by the family and they effectively become invisible, unable to access existing support structures. Being excluded, they run a greater risk of suffering mental, physical and sexual abuse.

Organisations working on behalf of displaced populations also need to consider their own approach to disability. In many cases, surveys and studies made of refugee or displaced children lack information about girls and boys with disabilities. Statistics usually only state the age and sex of the child, and seldom provide any analysis as to the prevalence of disability. UNHCR registration forms, for example, only categorise physical disability under their vulnerable groups heading.

It is essential to bring disability issues to the forefront when working with children. People working in these areas should consider their work from a disability

---

perspective, whether they are working with separated children or child soldiers, IDPs or refugees, whether they are working to mobilise communities or performing situation analysis. They should also consider their work from a disability perspective when they are dealing with issues such as health, sexual health, education, abuse and exploitation. Other ARC Resource Packs provide briefing and information about all these topics. The aim of this Resource pack is to highlight the issues around disability so that they can be applied in **all** situations where there are children and adolescents.

"We must be constantly asking the question whether children with disabilities are being given the same opportunities and rights as those without disabilities".

In situations of instability or in refugee camps, it is not always easy to start programmes of support for disabled children, but it is important to do as much as possible, otherwise valuable time will be lost when the child should be learning and developing.

Naomi Richman (1995): Violence and the Disabled Child.

THE SITUATION OF GIRLS AND BOYS WITH DISABILITIES IN TIMES OF INSTABILITY

The needs of children with disabilities are basically the same as those of other children, but in situations of conflict and displacement it becomes more difficult to ensure that these needs are met.

'Childhood is the time when nutritious food, good health, a stable environment, security, happy parents, caring adults, and daily structure and play are needed most. For the refugee child, these rights can no longer be taken for granted and the process of development slows down or even stops' ('Focus on Refugee Children, E. Segerström, Rädda Barnen 1995)

Although studies on the situation of children and adolescents with disabilities in conflict situations are limited, the effects of armed conflict and flight are most generally two-fold. On the one hand, the social environment, which might have lent itself to the development and promotion of their capacities before the conflict, is often disrupted or damaged. This situation affects the living conditions and endangers the survival of children and adolescents with disabilities. Those persons with disabilities who cannot cope with the demands of the flight into exile are often left behind. Problems for these girls and boys are made worse because most conflicts occur in developing countries where children are at a higher risk of impairment due to poverty and limited health care, and where resources for disability services usually do not have priority.

On the other hand, exposure to violence and arms (including landmines) means there is likely to be an increase in the numbers of children and adolescents with physical or mental impairments. According to the 1996 *United Nations Study of the Impact of Armed Conflict on Children*, armed conflicts in the previous decade had caused over a million deaths of children in poor countries. And for each dead child, three more had been injured or physically disabled and many more psychologically damaged.

RISK FACTORS FOR CHILDREN WITH DISABILITIES IN TIMES OF INSTABILITY

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 impairment or disability. The list below should encourage humanitarian staff to actively explore methods by which risk factors can be reduced, protective factors strengthened, and to adopt a disability perspective in their programmes and activities.

- The functioning of basic health services may be severely disrupted by a reduction of resources for preventative or curative health care and even the closure and/or destruction of health facilities.

- 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 (e.g. iodine, vitamins) can lead children and adolescents to 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.

- The separation of children and adolescents from their parents or caregivers often results in deprivation of special care and protection.

- A breakdown of traditional community structures may disrupt support mechanisms that community members with disabilities normally enjoy, and even lead to the (temporary) loss of normal support and coping methods.

- The exposure to violence and arms may result in large numbers of physical impairments such as, amputations, blindness, deafness, paralysis and facial disfigurements.

- There is a likelihood of psychological distress amongst children and adolescents increasing significantly during conflict 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 protective factors.

Poverty has a bearing on all of the risk factors associated with disability. Poverty indirectly causes impairments and disabilities as it is intrinsically linked to malnutrition, and prevents caregivers or whole communities from providing adequate health care to treat injuries and diseases. Poverty also disables children and adolescents through the lack of necessary resources for building schools and providing community services that give access to, or accommodate the needs of, persons with disabilities.

For more information on risk and protective factors for children and adolescents in situations of armed conflict and their relationship with trauma and resilience, consult the **Resource Pack on Child and Adolescent Development**, especially Topic 3. See also the **Resource Pack on Working with Children** which refers to communicating with distressed children.

ASSESSING THE SITUATION FOR CHILDREN WITH DISABILITIES

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 the refugee population, the need for effective assessment of their situation is clear. In addition to risk mapping, an assessment of the conditions of children with disabilities includes the identification and mobilisation of existing resources and approaches to supporting children with disabilities. The information will give the opportunity to identify those children or adolescents who require urgent health care in order to prevent the development or deterioration of impairments.

In order to examine the extent to which disabilities are affecting children and adolescents, humanitarian staff should tap into social and cultural understandings of disability and look for ways in which the social environment hinders access to available services or activities, and the full participation of children with disabilities. The consultation and involvement of the refugee community, in general, and of persons with disabilities (and their organisations) in particular, is crucial to the identification of existing resources, services and approaches to children and adolescents with disabilities. During this process, it should always be remembered that different societies may view disability in different ways. Humanitarian interventions should take account and make good use of existing local initiatives and coping methods towards disability.

Prompt Action in Assessing Needs: before action can be taken for treatment and rehabilitation, disabled refugees and others who may be at risk must be identified and their needs assessed. 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 and information from refugee leaders 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 disabled refugees will have impairments that are likely to become worse, some may even result in death, if proper medical care is not provided promptly.

Community Services Guidelines: Assisting Disabled Refugees (1996). UNHCR, Geneva (Pg. 32).

Responding adequately to the needs of persons with disabilities requires the adoption of a disability perspective in the needs assessment of the refugee population and this from the early stages of the emergency. 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.

How best to assess the situation?

As a first step in starting a programme, or finding out more about a situation, agencies usually conduct surveys or pre-studies to assess the situation for a specific target group, and/or to identify needs. In the book 'Disabled Children in

Developing Countries', P. Zinkin asks '*Who needs surveys?*' and '*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?*'

People with disabilities also criticise surveys because surveys about disabled people often focus on the individual aspects of the disability, instead of asking questions about the barriers in the society that actually could be changed. It is also difficult to carry out surveys about disability because the issue of definition of 'disability' is complex. 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.

Looking at functional difficulties instead of medical conditions can give useful information. A girl who experiences difficulty in walking may not be easily remediable. But maybe it is more important to know how happy she is, what opportunities she has for education and how she is viewed by her family.

In assessing the situation for children with disabilities, it would be helpful to include in the assessment information about how they, their families and communities cope with disability in different settings. Information about what kind of help has been developed locally for children with disabilities and what initiatives might be useful to try out in the future.

TRAINING MATERIALS FOR TOPIC 2

Overhead 2.1: Key Learning Points for Topic 2	Summary of key learning points
Exercise 2.1: Promoting Coping Skills for Disabled Children Affected by Conflict	Presentation followed by a ranking exercise and discussion which encourages participants to consider how to support disabled children more effectively
Exercise 2.2: Considering the Effective Use of Surveys	Practically based group discussion exercise
Handout 2.1: The Situation of Children with Disabilities in Armed Conflict and Displacement	Extract from a report by E. Åhlen, Radda Barnen, 1997
Reading 2.1: Violence and the Disabled Child	Reading by Naomi Richman (McKeith Press, 1995)

FURTHER SUGGESTIONS FOR TRAINING
Ask participants to bring with them to this training session copies of any situation analysis documentation or surveys that they have used recently (particularly with reference to displaced people; refugees entering a refugee camp situation, etc.). Having provided the input from this Topic, ask participants to work on these documents to devise a set of questions that would ensure that the situation for children and adolescents with disabilities was improved.

Disability
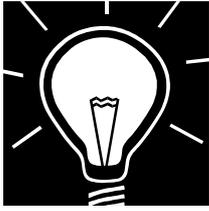
Topic 3
Legal Standards on Disability

KEY LEARNING POINTS

- *There are a number of legal standards providing for the effective protection, development and inclusion of children with disabilities.*

- *Children with disabilities enjoy equal rights with all other children, as set forth in the Convention on the Rights of the Child. They also have specific rights.*

- *The purpose of the UN Standard Rules is to ensure that girls, boys, women and men with disabilities exercise the same rights and obligation as others (the principle of equality of rights).*

The legal provisions relating to the protection, development and inclusion of children with disabilities are presented in various international instruments, which differ in their nature and importance. Treaties, also called conventions or covenants, are formal legal texts to which States become parties. They are considered as "hard law", because they create legal binding obligations. Other instruments, such as declarations, principles or rules, are non-binding on States, and are often referred to as "soft law". The provisions they set out are often more detailed than those found in treaties, and can therefore complement hard law. These instruments are authoritative standards because States participated in their elaboration and they reflect international consensus, i.e. States did not object to the provisions they contain. An example of soft law is the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities.

Although there are a number of international legal standards that can ensure effective protection, development and inclusion of children with disabilities, it is always necessary to verify the applicable legal framework for a specific country, including national and regional legislation.

THE CONVENTION ON THE RIGHTS OF THE CHILD (CRC)

The human rights of children are fully articulated in one treaty: the **Convention on the Rights of the Child**. The Convention protects children's rights by setting the highest standards in health care, education, legal, civil and social services. The approach of the Convention is holistic, which means that the rights are indivisible and interrelated, and that all articles are equally important. These rights are also to be applied within the principle of non-discrimination, meaning that they are the rights of every child, everywhere.

Moreover, certain articles of the Convention acknowledge specific rights and needs for various groups of children including: children affected by armed conflict and displacement, working children, children in conflict with the law and children at social and economic risk. In all these groups we find children with disabilities.

Two Articles of the Convention mention children with disability specifically:

Article 2.1: "States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective to the child's or his or her parents..disability..or other status".

Article 23 addresses their special needs: "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".

The rights of the girls or boys with disability are not limited to aspects raised in Article 23 - every article that refers to 'the child' also applies to the child with disabilities. Children with disabilities should be given the same opportunity to enjoy an adequate standard of living. They have the right to play, the right to survival and development, the right to express opinions in matters affecting them, the right to a family, a name and a nationality, but also the right to access education, health care, rehabilitation services, and preparation for employment.

The approach of the Convention being holistic, and all the rights being interrelated and indivisible, the Convention constitutes a powerful tool for the protection and guarantee of the rights of children with disabilities.

REFUGEE AND DISPLACED CHILDREN

Article 22 of the **Convention on the Rights of the Child** relates specifically to refugee children and states: "States Parties shall take appropriate measures to ensure that a child who is seeking refugee status or who is considered a refugee.., receive appropriate protection and humanitarian assistance in the enjoyment of applicable rights set forth in the present Convention and in other international human rights or humanitarian instruments to which the said States are Parties".

In refugee law, the **1951 Convention relating to the Status of Refugees** is applicable to refugees with disabilities, as it applies to all refugees, including children, without discrimination (Article 3). Other provisions relevant to refugees with disabilities are: **Article 24** - "States parties shall accord to refugees staying in their territory the same treatment as is accorded to nationals in respect of social security, for the legal provisions…on disability"; **Article 7** - "Except where this Convention contains more favourable provisions, a Contracting State shall accord to refugees the same treatment as is accorded to aliens generally", notably self-employment (Article 18), liberal professions (Article 19), housing (Article 21) and education (Article 22).

In humanitarian law, under the **Protocol Additional to the Geneva Conventions of 12 August 1949, and relating to the Protection of Victims of International Armed Conflicts** (1977), the terms "wounded" and "sick" means persons, whether military or civilian, who, because of trauma, disease or other physical or mental disorder or disability, are in need of medical assistance or care and who refrain from any act of hostility. All the wounded and sick, to whichever Party they belong,

shall be respected and protected…and shall receive, to the fullest extent practicable and with the least possible delay, the medical care and attention required by their condition (articles 8 and 10).

The **Guiding Principles on Internal Displacement** (1998), reflect the concerns of persons with disabilities. The document includes disability in the non-discrimination clause: the principles should be applied without any discrimination of any kind such as...disability (principle 4). Principle 19 states: "All wounded and sick internally displaced persons as well as those with disabilities shall receive to the fullest extent practicable and with the least possible delay, the medical care and attention they require…"

Landmines pose a particular threat to children and injuries often lead to disabilities, if not death. The **1997 Convention on the Prohibition on the Use, Stockpiling, Production and Transfer of Anti-personnel Mines and on their Destruction** (known as the Ottawa Treaty to Ban Landmines) states in its article 6.3 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…"

UN STANDARD RULES ON THE EQUALISATION OF OPPORTUNITIES FOR PERSONS WITH DISABILITY

Towards the end of the 1960's organisations of persons with disabilities started to formulate a new concept regarding deficiency. That new concept indicated the close connection between the limitation experienced by people with disabilities, the design and structure of their environments and the attitudes of the general population. In the 1970s, United Nations initiatives embraced the growing international concept of human rights of persons with disabilities and equalisation of opportunities for them. In 1975, the General Assembly adopted the "Declaration on the Rights of Disabled Persons" (General Assembly Resolution 3447(XXX)), which proclaims the equal civil and political rights of disabled persons.

1983 - 1992 was declared the United Nations Decade of Disabled Persons by the General Assembly. In 1990, the UN Economic and Social Council (ECOSOC) authorised the Commission for Social Development to elaborate standard rules on the equalisation of opportunities for disabled children, adolescents and adults. This was to be done in close collaboration with the specialised agencies of the UN, other inter-governmental bodies and non-governmental organisations, especially organisations of disabled persons.

The outcome was the **UN Standard Rules on the Equalisation of Opportunities for Persons with Disability**, that was adopted in 1993 (General Assembly Resolution 48/96). Although not a legally binding instrument, the Standard Rules represent a strong moral and political commitment of Governments to take action to attain equalisation of opportunities for persons with disabilities.

"Equalisation of opportunities" means the process through which the various systems of society and the environment, such as services, activities, information etc, are made available to all, particularly to persons with disabilities. The principle of equal rights implies that the needs of each and every individual are of equal importance, and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. The Rules state that special attention may need to be directed towards groups such as women,

children, the elderly…and refugees with disabilities who have special needs requiring attention.

Four important preconditions for equal opportunities are defined (awareness-raising, medical care, rehabilitation and support services), and eight target areas are identified (accessibility, education, employment, income maintenance and social security, family life and personal integrity, religion, culture, recreation and sports). The implementation of the Rules is monitored within the framework of the UN Commission for Social Development.

Another noteworthy initiative, in 1994, was the meeting of governments and representatives from several UN agencies and non-governmental organisations in Salamanca, Spain to further the objective of Education for All, particularly those with special educational needs. 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.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITIES AND HEALTH.

In May 2001, the 54th World Health Assembly endorsed the World Health Organisation's (WHO) second edition of the International Classification of Impairments, Disabilities and Handicaps (ICIDH-2), giving it a new title, the **International Classification of Functioning, Disabilities and Health**.

ICIDH-2 is a multipurpose classification designed to serve various disciplines and different sectors. Its specific aims can be summarised as follows:

- to provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants;

- to establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities;

- to permit comparison of data across countries, health care disciplines, services and time;

- to provide a systematic coding scheme for health information systems.

Although ICIDH-2 is inherently a health and health-related classification, it is also used by sectors such as insurance, social security, labour, education, economics, social policy and general legislation development. It has been accepted as one of the United Nations social classifications and is referred to in and incorporates *the Standard Rules on the Equalization of Opportunities for Persons with Disabilitie*s. ICIDH-2 thus provides an appropriate instrument for the implementation of stated international human rights mandates as well as national legislation.

TRAINING MATERIALS FOR TOPIC 3

Overhead 3.1: Key Learning Points for Topic 3	Summary of the key learning points
Exercise 3.1: Needs and Rights Exercise	A discussion exercise designed to encourage participants to consider needs and rights for all children and how they might differ or not from those of children with disabilities
Exercise 3.2: Children with Disabilities and Their Rights	A research and discussion exercise which provides an opportunity for participants to consider the CRC in terms of how it relates to children with disabilities and adolescents
Handout 3.1: All Children are Born with Rights - Relevant Articles from the CRC	Articles from the Convention on the Rights of the Child relevant to disability

FURTHER SUGGESTIONS FOR TRAINING

Brainstorm with participants all of the obstacles that children with disabilities might have to face in their daily lives and then get participants to work together in small groups to cite legislation (or lack of it) which should help them.

Use the following questions as a basis for discussion:

1. Have CRC/Standard Rules been translated into your language?

2. How can you use these two documents in your sphere of work?

3. Is monitoring and follow up of the CRC and/or the Standard Rules part of your present work?

4. Is disability an aspect in this work?

5. What is the potential for ensuring the participation of children with disabilities in the planning and development of work?

Provide copies of the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, and the Salamanca Statement as further reading for Senior Managers and Sector Co-ordinators and develop an exercise where they research the documents to find which aspects of it would serve as useful advocacy in their own working situations.

Disability
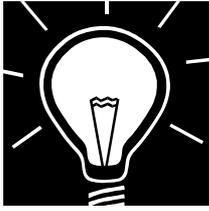
Topic 4

Different Models and Approaches to the Issue of Disability

KEY LEARNING POINTS

- *Analysis of disability models can inform effective approaches.*

- *Various strategies exist but every situation is likely to be different, and so specific approaches must be adjusted accordingly.*

- *Sound COMMUNICATION with, and PARTICIPATION of, children with disabilities and their families will be essential.*

- *Children and adolescents with disabilities are likely to be disadvantaged on multiple levels and so close cross-sector approaches are necessary.*

As stated previously, disability is understood in different ways according to culture, attitudes and prevailing social norms. The way in which a person's disability is perceived dictates the way that it is approached and handled.

The traditional approach to disability has been informed by the medical/individual model but increasingly, attention has been placed on a social model of disability which highlights the interaction between persons with disabilities and their environment. The actual approach that will be adopted in a given situation will vary according to the circumstances, but it is important that the chosen approach is based on assessment of prevailing social norms. Sound communication with, and participation of, children with disabilities and their families will be essential to any successful approach.

In general terms, approaches to disability can be placed on a continuum with a medical/individual model, on one side, and a social model, on the other.

- firstly, and more traditionally, there is the **individual/medical model**, where the "condition" can be medically diagnosed and treated. The implication is that the person with the disability is seen as the "problem" (she/he can't see or can't walk or can't understand), and used in isolation this model is analogous with attempting to adapt the person to fit better into society.

- the second is the **social model**. Using this model, the "problem" is not seen to be the person with the disability, but rather the society in which that person lives. The society does not provide for the needs of people with disabilities (inaccessible buildings, no braille books, no sign language interpreter, etc.) and thus *disables* the person by not allowing for their inclusion. The challenge is for the society to adjust or to accommodate persons with disabilities.

Overheads 4.1 and **4.2** provide diagrammatic representation of these models.

THE INDIVIDUAL/MEDICAL MODEL

For many decades, the individual/medical understanding of disability has prevailed in many societies and has informed policies and services accordingly. The individual/medical model of disability is based on two principles. Firstly, disability is considered to be an individual phenomenon, in the sense that the problem originates in the person him/herself. Secondly, it emphasises the medical nature of disability, as objective measures are believed to exist to diagnose the individual impairment and treat the abnormality. The impairment, either hereditary or resulting from malnutrition, illness, injury or trauma, is perceived as the primary cause of the disability and of the separation, exclusion or isolation that disabled persons experience in society.

Within this model, medical rehabilitation is seen as the most effective response. The aim of medical rehabilitation is to correct and compensate for the person's deviation from what is perceived normal, and to help the disabled person to attain his/her maximum potential to carry out and participate in daily and social activities. This type of rehabilitation requires specialised services and institutions (e.g. special education, special training in communication), which rely on medical and paramedical personnel and often on expensive techniques and tools.

The reality for many is that such specialised services simply do not exist, and neither are resources available for their establishment. Also, a concern that is often expressed with policies and programmes that are based entirely on this model, is that they often convey the image of persons with disabilities as being dependent, helpless, abnormal, and a burden or cost to society.

> *'My mother was constantly visiting the hospital to see about an operation for me, to change my callipers, to consult the doctor about my condition. At the age of seven when I started primary school she had to carry me on her back several kilometres each day. It put a strain on family life.... I began to sense they wanted me away, that the family wanted a rest from my problems. I suppose they also thought that away from home in an institution I might have better chance of improving myself'.*
>
> *Abdelmalk 8 years old born in Fez, Morocco 'In our own Words', SCF UK.*

SOCIAL MODEL

Since the 1960s, a new model to disability has been gaining wide recognition. The growth of local, national and international movements and organisations that advocate the rights of persons with disabilities and strive for equal opportunities have stimulated the process.

This alternative model highlights the close connection between the limitations experienced by individuals with disabilities, and the surrounding environment. Just how disabling an impairment may be, depends on the social and individual attitudes towards disability and the structure of the society. Knowledge about the nature and causes of disability may be based on superstition, or religious and cultural beliefs. Having a child with disabilities may be regarded as shameful or as a punishment of God. Consequently, in many cultures, girls and boys with

disabilities find that their human dignity is impaired: not only do they have to struggle with their own disabilities, but they also have less opportunities for individual development. Children who are kept away from other children and from society as a whole have fewer opportunities to learn and develop. Moreover, a society that does not see, interact or engage with those in the community with disabilities will never have to review or challenge its own prejudices and understandings of disability.

Therefore, the social model to disability examines how the social environment *disables* the person. It is often the society's response (e.g. separation, stigmatisation) or lack of response (e.g. inaccessibility of services) to the impairment or disability that forms the basis of the social disadvantage experienced by persons with disabilities.

Rather than targeting individuals, rehabilitation strategies are directed towards the society in order to make them more accessible to all, ensuring inclusion in social activities and services. The needs of persons with disabilities have to be explicitly taken into account in the policies, programmes and projects developed at local and national levels. Persons with disabilities should have access to ordinary services, which are strengthened by the support of specialised services.

The social model of disability challenges the negative portrayal of disabled persons, which is sometimes characteristic for the individual/medical model. Movements and organisations of persons with disabilities (and their families) have pointed towards the capacities of persons with disabilities. Not only are people with disabilities capable of taking an active part in daily and social activities, but also in the planning of services and programmes that affect them.

CAUTIONARY NOTE

This division of models is helpful, especially in terms of understanding differences in approaches and underlying attitudes, as well as in developing an analysis of different perspectives including the biological, individual and social factors involved. However, models cannot be relied upon as the only starting point for work with disability. The reality of each situation for a child or an adolescent with a disability is far more complex and the approach adopted will have to be varied according to circumstances.

It should also be remembered that the adopted approach will require close cross-sector collaboration as many issues may have to be addressed, from health to housing, and from education to participation. Also, each child may be disadvantaged on multiple levels - she may be a girl, she may be separated from her family; she may come from an ethnic minority group; she may have mental disabilities. It is therefore important to consider the issue of disability *alongside* other issues and social relations that may be affecting the child.

N.B. Cross-referencing can be made to other **ARC Resource Packs** on issues such as **Community Mobilisation**, **Situation Analysis**, **Education**, **Reproductive Health**, **Separated Children**, **Voluntary Repatriation** etc.

STRATEGIES FOR WORKING WITH PEOPLE WITH DISABILITIES

Having provided the cautionary note, it is clear that by including the "social model" of disability as a guiding principle, children and adolescents are more likely to have their needs and rights met. Over the last twenty years, and using the social model as a guiding principle, a number of strategies for working with children with disabilities have developed. Some of these are described briefly below.

It is important to point out that no one way is better than another. 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.

Community Based Rehabilitation (CBR)

CBR is a widely used method of working with children with disabilities. It was originally developed by WHO in the 1970s, and involved using available local means to assist people in the child's local environment to help the child take part in any activity where other children were represented. To make CBR effective, society as a whole must be persuaded to take collective responsibility for members of their community with disabilities. Parents, neighbours and relatives should receive training about how they can help and support the child. Teachers in school must be given advice as to how to adapt their teaching to children with special needs; parents must be shown how to assist their children with essential exercises, and so on. The purpose of CBR is to change the attitude of both the child with disabilities and that of other people in the environment. If one can make the child with disabilities more visible in the community, it is also easier to make them more accepted. They need to be inspired to want to take part in everything that goes on in the local community, while at the same time it must be made possible for them to participate. According to the CBR concept, most problems facing adults and children with disability could be solved at the community level, with support from national and regional levels.

The CBR method has been tried in several variants in more than 50 countries. Initially, it was applied in rural areas and only subsequently in urban areas. It is now being tried in slum districts and refugee camps. However, even though the CBR approach has succeeded in making people with disability visible and enabled integration in the society, there are still more hurdles to cross: the participation of adults and children with disability in decision making processes is still, to a large extent, not realised. It has also been shown through experience that the CBR approach has not succeeded in "mainstreaming the disability issues", i.e. issues concerning children and adults with disabilities are still treated separately.

CBR is a low cost strategy, because it is meant to be included in societies 'normal' functions. However experience shows that often the development of a CBR system within a community will have the added benefit of triggering other community based activities, thus making the strategy more effective while still operating at a relatively low cost.

See **Disability Reading 4.1** for more information about CBR

Outreach Programmes

These are activities that have their origin in institutions like hospitals, rehabilitation centres or special education units. Often these activities have started when

professionals have realised that not all people with disability have access to the services provided at the 'institutions'. Professionals from these institutions travel to the community, providing services at the community level.

The main difference between CBR and Outreach programmes is the underlying attitude towards disability. In the CBR concept the human rights perspective is strong. Social integration, participation and empowerment of people with disability are corner stones. Outreach activities are based upon a professional, often medical point of view and deal mostly with the individual problem of the person with disability.

Both the Outreach programmes and the CBR have benefited people with disabilities. Both strategies have resulted in the issues of disability, and people with disabilities becoming more visible. However when planning and implementing programmes for *children*, the children with disabilities within that group are still very often 'forgotten'. If they are considered at all then they are singled out as a special group described as needing special care. This often results in them becoming low on the priority list, not least in a refugee situation.

Inclusion

Wherever possible, children with disabilities should be involved in normal activities with other children. 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 that they are not marginalised and their capacities and special strengths are promoted.

Inclusion means that whenever there are activities planned for adults and children, consideration about the adults and children with disabilities should be automatic. The term "inclusion" should not be confused with the term "integration" which refers to the process of returning to his/her community someone who previously has been segregated.

Inclusion refers to the maintenance of the individual in the natural environment, thus avoiding initial segregation. In terms of working with children, *inclusive education* is a concept which has been strongly promoted in recent years. It is a relatively new concept which requires changes in attitudes towards children with disabilities. Children are not be "integrated" as they have never been "segregated". 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 the diversity of people by accommodating all children (The Salamanca Statement, 1994).

UNHCR'S APPROACH

This section looks at the general approach that has been adopted by UNHCR. The principles underlying the approach were elaborated in the UNHCR Community Services Guidelines on **Assisting Disabled Refugees: A Community-based Approach** (1996).

These Guidelines are designed to enable those working with refugees to understand the causes and effects of disability on refugees and to look for solutions. The guidelines provide practical guidance to steps that should be taken

and are based on the concept of community-level care. UNHCR's approach focuses on two main areas: prevention and treatment, and rehabilitation.

- Prevention and treatment: concrete efforts are to be made to prevent the incidence of potentially disabling impairments. UNHCR-assisted health, education and social services are to be designed and implemented with specific attention to the early detection and, as appropriate, treatment of disabling conditions. Prevention takes place at different levels:

  Primary: includes measures taken to eliminate or reduce the occurrence of mental, physical or sensory impairment. Preventive strategies at this level involve water and sanitation, physical planning, health, social and educational services.

  Secondary: involves the early identification and treatment of a condition so that it does not result in a disability. Preventive strategies at this level would involve preventive and curative health services.

  Tertiary: aims at preventing the impairment from becoming a disability. Measures at this level include screening, parent education and provision of appropriate aids. An accompanying programme of public education at all levels is essential, so that groups who are at risk, and their families, are not only informed but motivated to participate in the implementation of the preventive measures.

- Rehabilitation: field offices are to seek to ensure that disabled refugees have access to the same rehabilitation services as nationals. Where individuals suffer physical, mental or sensory disabilities related to their situation as refugees, appropriate rehabilitation services are to be provided as **basic components** of UNHCR's assistance programme. The rehabilitation is to be provided at the earliest time possible in the development of a refugee situation with a view to promoting the self-reliance of disabled refugees and their families.

UNHCR projects are to be designed and implemented so as to maximise the **participation** of disabled refugees, including refugee children. UNHCR offices in the field are to ensure that disabled refugees have **equal access** to and opportunities in education, housing, transportation, health and social services as well as aspects of the social, cultural and religious life.

UNHCR also assists refugees with disabilities by evacuating them abroad to neighbouring countries for the necessary treatment when local facilities are inadequate.

> "…disabled refugees fall within the existing legislation of the countries in which they are seeking asylum. In countries where they are not granted refugee status, but are being assisted by UNHCR as 'mandate refugees', field offices attempt to ensure, through liaison with local facilities (government and NGO), that these refugees benefit from the assistance being offered to local citizens. This is usually done on a case-by-case basis.
>
> Community Services Guidelines: Assisting Disabled Refugees (1996, Pg. 8).

UNHCR's **Refugee Children: Guidelines on Protection and Care** (1994) states that "all efforts must be made to meet the special needs of disabled refugee children" (see pages 71-77). The guidelines also focus on prevention and rehabilitation, especially community-based rehabilitation, and integration of disabled refugee children.

It should also be noted that UNHCR has signed a **Memorandum of Understanding with the World Health Organisation** (1997), that has as one of its general objectives, "to reduce the mortality, morbidity and disability among the beneficiaries and to provide them with health services…".

TRAINING MATERIALS FOR TOPIC 4

Overhead 4.1: Key Learning Points for Topic 4	Summary of the key learning points
Overhead 4.2: The Individual/Medical Model of Disability	Diagram illustrating issues surrounding disability when the disabled person is seen as the "problem"
Overhead 4.3: The Social Model of Disability	Diagram illustrating issues surrounding disability when "the disabling world" is seen as the problem
Exercise 4.1: Looking at Different Approaches to Disability	Presentation and discussion exercise analysing the strengths and weaknesses of the different approaches to disability
Exercise 4.2: Different Approaches - Case Study from Nepal	Uses a case study to provide further reflection on the strengths and weaknesses of differing approaches. This case study also provides a model of good practice
Handout 4.1: Extract from UNHCR Guidelines on "Assisting Disabled Refugees"	Types of intervention
Reading 4.1: A Description of Community-Based Rehabilitation	Reading to support a better understanding of CBR

FURTHER SUGGESTIONS FOR TRAINING:

- Using Disability Handout 4.1 as an introduction, invite participants to identify a refugee situation with which they are familiar (participants may have to work in small groups for this exercise) and ask them to rank both the general and the specific interventions discussed in this document in order of what they consider to be most important in their own particular situation.

- Ask participants to perform an analysis of UNHCR's general approach to disability in relation to the two models presented at the beginning of this topic.

Disability
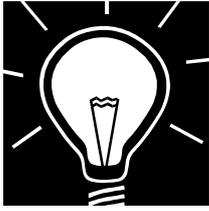
Topic 5
Excluded Children

KEY LEARNING POINTS

- *The reasons why boys and girls with disabilities are often excluded lies with prevailing attitudes and lack of understanding in society as a whole.*

- *From policy development, through planning and design, and on to implementation the views of children are rarely taken into account.*

- *Children with disabilities are not one homogenous group. Like all boys and girls they are all different individuals with differing needs.*

- *From birth, children with disabilities can be excluded from accessing the very support they need for their development.*

WHY ARE BOYS AND GIRLS WITH DISABILITIES EXCLUDED?

Boys and girls with disability are often excluded from activities in the society because they are looked upon as 'strange' or 'special'. Possibly, our own experience of people with disabilities confirms this. A large majority of us have grown up in a segregated society. We do not have disabled friends, neighbours or partners, our children do not bring home disabled playmates. If we do, then we see them as the exceptions, the heroes, the brave, the remarkable. This very simple factor perpetuates exclusion through lack of basic knowledge and awareness about children and adults with disabilities. Quoting from the UN Standard Rules on the Equalisation of Opportunities for Persons with Disability, "*Ignorance, neglect, superstition and fear are social factors that throughout the history of disability have isolated persons with disability and delayed their development*".

Five year old Fatima is an Afghan refugee child living in a camp. She was affected by Polio at the age of two. She cannot walk and she has also developed some strange behaviour. Parents are worried about her future, being a female she has never been to the doctor as it is a mere wastage of money for a girl child. The parents feel she is a result of some sin.

Because society as a whole often makes little effort towards the integration of boys and girls with disability, this results in the child being forgotten and her/his social needs being neglected: the child *behind* the disability is seldom seen.

POLICY DEVELOPMENT

Children as a whole are marginalised within the development process at both local and national levels. From policy development, through planning and design, and on to implementation their views are rarely taken into account. Lack of awareness and understanding of the development needs of children with disabilities means that they frequently become further marginalised within the general children's agenda.

At an international level too, certain groups of children tend to be more fashionable and appealing than others, attracting more media profile and more funding for projects. Certain themes become fashionable at certain times for all sorts of political reasons. Currently, topics such as 'child labour' and 'child soldiers' are likely to elicit more interest and money from donors than 'disabled children'.

In addition, programmes and policies focusing on 'street children', 'refugee children', 'child labour' or 'sexual exploitation' rarely include disabled children either implicitly or explicitly. However as already mentioned, disabled children will be found in any such groupings.

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

In the book *"Prejudice and Dignity"*, E. Helander suggests that most developing countries don't have a clear policy related to people with disability, which probably reflects negative attitudes.

Where communities lack access to basic resources, families with disabled members are frequently the poorest and most marginalised. Poor children are malnourished and they are subject to increased infections and little access to proper treatment. They are more exposed to unsafe water and hazards in their homes - all of which may cause permanent damage.

In the experience of Save the Children, even the very poorest families initially try to care for and protect their disabled child, but with negative beliefs, behaviours, lack of information, knowledge, skills and resources, the family becomes trapped in a cycle of poverty and exclusion.

BOYS AND GIRLS WITH DISABILITIES ARE NOT A HOMOGENOUS GROUP

The general usage of the term 'The Disabled' usually implies a cohesive and homogenous group. However, these children are boys and girls; they have different ethnicity; 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.

Girls and boys with disabilities also have different experiences depending on what disability they have. Disabled children are a diverse group with a wide range of experiences, skills and perceptions of their own identity. Discrimination and prejudice are as common among disabled people as in other sectors of the society: racism, sexism, are all present.

> People with the most severe impairments, especially learning disabilities and disabilities which affect conventional methods of communication, are particularly marginalised within the disability community.
>
> (Disabled Children in a Society at War, OXFAM 1997).

Boys and men who have moving difficulties have in most societies 'higher' status than girls. In many societies there are more boys with disabilities than girls - they survive longer. The girl with disabilities is more likely to be abandoned, to be discriminated against, to be excluded from education, to be deemed unmarriageable and to be excluded from motherhood and general participation in their society.

The point remains that, whether less or more marginalised, boys and girls with disabilities are often excluded from society at large.

> In one Save the Children programme in Africa, a blind child was asked to speak about his experience of education to the Save the Children staff. He was confident, eloquent and very clear about his abilities, his rights, his ambitions. Staff were incredulous – they had never imagined a disabled child could speak like this. Some even asked whether the child had been trained beforehand.

HOW ARE GIRLS AND BOYS WITH DISABILITIES EXCLUDED?

Because children with disabilities have been viewed as needing special care - one has consequently viewed the child as 'special'. This view has and still is, in fact, contributing to alienating children with disabilities rather than accommodating their needs. People think that as children with disabilities are considered "special", only special teachers, and specially trained health staff can 'take care' of these children. Parents have not been encouraged or allowed to participate and learn and also contribute with their experiences. This has left many parents feeling 'powerless' and putting too much trust in the 'professionals'.

The professionals, trained in caring for children with "special needs" have, in their efforts to make their specialities and knowledge more valuable, endorsed 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 they are like other children - all are special and have special needs at certain times. However their rights are the same all the time.

> "Partly because the disabled persons are given so little chance to take part in the life of the community, everyone assumes that they can not and should not. Disabled people often grow up as outsiders in their own village or neighbourhood. They are unable to work, unable to marry and have children, unable even to move about and relate freely to others in the community. This is not because their disabilities prevent them, but because society makes it so difficult".
>
> (David Werner 1987 Disabled Village Children).

EXCLUSION FROM EDUCATION

Education for children with disabilities has generally been provided (if indeed there has been any) at schools segregated from mainstream schools. Instead of changing the school system, and negative attitudes among professionals and other children, children with disabilities have been removed from their usual environment to receive special care in special institutions. Including children with disabilities in school is still rather rare and most of them are denied education.

It is a common fact that schools and teachers often say they cannot include children with disabilities in their classrooms. Often, the justification for this argument is that they need 'special care' and 'special teaching'. However the reality is that by characterising children with disabilities as special and placing them in special institutions, the attitude that they are "special" is perpetuated. Additionally the fact of removing children from their environment makes them somehow different, as well as removing opportunities for social interaction with other children, such as play. The result is a self-fulfilling prophecy.

EARLY CHILDHOOD EDUCATION

From birth, children with impairments can be excluded from accessing the very basic support for their development that all children need; they are kept hidden and excluded from daylight, from ordinary environmental stimulation, from physical contact, from general stimulation for their movement and language development. Lack of sufficient early childhood care, stimulation and education cannot be compensated for in later life – this is a crucial and unique stage in a child's life.

In Anhui province in China, kindergarten teachers were trained to make their teaching methods more child focused and to respond to individual needs through team teaching and flexible methodology. This enabled two children with mental disabilities to be included in each class, despite large class sizes and few resources. The new methodology not only benefits the children with mental disabilities, but has resulted in improved education for all the children.

In many countries there is no organised kindergarten system. Often parents will wait many years after they have realised that their children are 'different', hoping that they will learn to walk or talk in their own time – often this means that the children miss out on crucial support to their development in the early years. Once community-based programmes become established and known about in the community, parents start to seek help for their children much earlier, and local volunteers or parent support groups can provide appropriate advice and training which enable the children to develop their basic skills.

PRIMARY SCHOOL EDUCATION

In the experience of Save the Children programmes, children with disabilities are excluded from local primary schools in many different ways (these points are also presented as **Disability Handout 5.2**).

One common reason is very simply that parents and the community do not know or believe that children with disabilities can be educated, that they can learn and

develop.

Parents are ashamed of their disabled children and wish to keep them hidden. Even if they are not ashamed, overprotection will often mean that they keep their children indoors and away from school. And if they do not keep their children hidden, often neighbours will criticise them for allowing disabled children to be seen outside the house.

In many primary schools, teachers are poorly trained and the curriculum is often rigid and not very relevant to local communities. In many cases children with disabilities are left at the back of the class, repeating years, failing and dropping out. Teachers do not have the necessary knowledge and skills and so, even though the children are sitting in the classroom, they are excluded from education.

A simple programme of training and awareness raising for teachers not only enables those children with impairments to benefit, but also makes teaching more child focused and reduces drop-out and repeater rates for all children.

In many rural areas schools can only be reached by long walks; there is no public transport or roads, and mobility-impaired children cannot access them.

But 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. Compared to us the others who failed their exams were disabled and had a handicap. But I think it is people's abilities one should focus on, not the things they can't do.'

(In our own Words, SCF UK – Abdelmalik from Morocco)

TRAINING MATERIALS FOR TOPIC 5

Overhead 5.1: Key Learning Points for Topic 5	Summary of the key learning points
Overhead 5.2: Factors Influencing the Extent to which a Child with Disabilities is Excluded	The four key factors that can lead to exclusion.
Exercise 5.1: Considering Excluded Children – Case Study from South Lebanon	Uses a case study from South Lebanon to enable participants to consider the issues of excluded children in their own working situations
Exercise 5.2: Why are Children with Disabilities Excluded from Primary School?	Discussion exercise, enabling participants to consider issues relating to the ability of children with disabilities to attend school
Handout 5.1: Picture taken from 'Focus on Refugee Children' by Eva Segerstrom, Radda Barnen	Drawings that can be used to stimulate discussions about disability
Handout 5.2: Reasons why Disabled Children Might be Excluded from Primary Education	Summary of lessons learned by SCF

FURTHER SUGGESTIONS FOR TRAINING

- Ask participants to share their experiences about what percentage of children with disabilities attend schools in their own areas; the different types of disabilities; the different ways of handling them.

- Using the picture from **Disability Handout 5.1**, ask the participants to look at the picture of the boy watching other children playing. Talk about the picture (provide others if possible) and ask the participants to consider what this boy is feeling; what the other children are feeling.

- Using training methods from **ARC Facilitators Toolkit**, such as **Situation Cards**, or **Dilemma Boards**, devise a number of situations where participants have to decide whether or not the child in that particular situation would be able to attend school. What extra support might s/he need; and who would be responsible for providing that support? For example: a nine year old girl who needs to use crutches; a fourteen year old girl with mental retardation; a five year old boy who is blind; an eight year old boy with cerebral palsy.

Disability

Topic 6
Action Towards Inclusion

KEY LEARNING POINTS

- *There are a number of ways of encouraging changes of attitudes towards disability and promoting inclusion.*

- *Attending school provides continuity, creates a sense of normality and promotes social interaction for all children, with disabilities or not.*

- *Inclusive education is primarily about transforming or building an education system which responds to the real diversity of children.*

- *The role of the school should be to reinforce the abilities of all children and support all children's potential for learning.*

- *Education is a basic right and, contrary to common belief, making education inclusive can improve access and quality for all.*

WORKING TO CHANGE ATTITUDES

The issue of disability has been gaining a higher profile over the last decades, especially in the field of Human Rights. Although there has been considerable progress in the area of legal standards and policy-making in relation to disability, understandings, attitudes and behaviour towards disability change at a slower pace.

> "The liberation of disabled people is ultimately a question of justice and rights enshrined in law, made real by the empowering relationships that come from a genuine understanding by the rest of us".
>
> (P. Coleridge: Disability, Liberation and Development).

The social model of disability, which was outlined in **Topic 4**, 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.

This topic considers a number of issues that will be important in promoting and strengthening the inclusion of children and adolescents with disabilities. Particular attention is paid to the important role that education can play in this process.

To change the situation for people with disability, 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.

Establishing or strengthening organisations of persons with disabilities
The mobilisation of persons with disabilities is an important step towards the inclusion of children and adolescents with disabilities. Organisations for persons with disabilities have increasingly engaged in defending the rights, needs and priorities for children and adolescents with disabilities.

Organisations of persons with disabilities need to 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.

Contact
Changing of attitudes also occurs when people meet each other in a social context. Such inter-action can lead to developing better common understanding. If people with disabilities are part of the society, are visible and speak for their own cause, this will allow opportunities for non-disabled people to change their perceptions. People will get to know the person behind the disability.

Societies consist of individuals, and the society cannot be changed unless individuals changes. A change in attitudes must therefore start with the individuals and their attitudes towards themselves and others. Attitudes can drastically change when people see how those with disabilities are able to develop and handle things on their own. If they can present themselves as strong and capable individuals (refuse to see themselves as victims), people with whom they come into contact will treat them as strong and capable.

People can be influenced through contact and information, but legislation is also important. National law expresses the value that a given society holds. Legislation is the base from which to advocate for change, so that laws can be reinforced.

A starting point for action towards inclusion could be to examine one's own attitudes, feelings and motivation in relation to supporting different rights campaigns, and to see whether our 'prioritising' reflects our own bias or some sort of 'objective' reality. Disabled children are everywhere, they lack access to basic rights, and yet simple inclusive policy making and programme implementation can realise their rights. Often, commitment and openness, not simply resources, are the keys to success.

Collecting and Disseminating Information
Considerable efforts may be required in order to upgrade or establish a statistical information system on disability, especially in 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 of all new arrivals in the refugee camp as well as of subsequent data collection or surveys. Information on the types of disability, the extent to which that disability affects the population, and the available services within or outside the camp should be gathered and processed.

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, why it happens etc. People with disability are potentially their own most influential advocates: their own perception of themselves will be transmitted to others.

Training and capacity building
Parents, neighbours, relatives, community groups and community leaders are all likely to benefit from receiving training about how they can help and support children with disabilities, and promote inclusion. Discussions should aim at encouraging adults to communicate with children about their situation, and ensuring their integration and participation in the wider community, especially in schooling. Teachers in school must be given advice as to how to adapt their teaching to children with special needs; parents must be shown how to assist their children with essential exercises, and so on.

> 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 disabled children, and ensure they are not marginalized, and that their capacities and special 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 disabled children (Child-to-Child 1993).
>
> Naomi Richman (1995): "Violence and the Disabled Child".

Local community workers, whether health or social, should be trained to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services. Trained health advocates, who need not be health workers, could convey important explanations and provide information to children and families. 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.

Providing an Enabling Environment
Promoting the inclusion of children with disabilities in regular activities will require more than simply providing assisting 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 and implement 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 a basic criteria for their work.

Even though the plight of children with disabilities becomes much harder in conflict situations, there are many actions that can promote their well-being. In broad terms the aim of such actions should be to create a feeling of normality within the given situation, and to re-establish a sense of self-worth for the child. Education, or

at least similar structured activities, can play an important role in achieving both of these objectives.

Participation

As has already been highlighted, it is essential that children with disabilities and their families are able to participate in policy and decision-making fora, project design and implementation. 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 these children to participate in activities within the community. People need to understand that stimulation, play, games, love, and security are as important for these children as for other children. Even if a child has difficulty with moving, we should help this child to develop on her/his terms. Participation is possible if children with disability are given opportunities, and their ideas are heard.

In situations of instability it is not always easy to start programmes of support for disabled children, but it is important to do as much as possible, otherwise valuable time will be lost when the child should be learning and developing.

Such situations, however, may provide opportunities for social change. In *'Disabled Children in a Society at War'*, Lisa Gillham discusses such changes that occur in a time of conflict, and how they can be conducive to the introduction of new ways of thinking. She refers to the situation in Bosnia:

"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." (Fiona Gell, ibid.)

INCLUSIVE EDUCATION

Improving Access to Education

In terms of girls and boys with disabilities, access to appropriate education is one of the key ways of supporting their development.

In 1948 the United Nations proclaimed education to be a basic human right and between 1950 - 1979 enrolments in schools rose on a global level. However, in many developing countries, in villages, in shantytowns and in refugee camps, children were not at school. This was especially the case for rural girls and children with disability. These children were denied education. In the course of 1980s, growth in educational opportunities for children in developing countries

slowed down. In theory, educational systems were made available for all children, but the opportunities for children with disabilities to be enrolled were often severely restricted. Although much money was often spent on services for children with disabilities in different schools and institutions, these services rarely reached more than a fraction of the children in need.

In June 1994, representatives of 92 governments and 25 international organisations met in Salamanca, Spain, to further the objective of Education for All by considering the fundamental policy shifts required to promote the approach of inclusive education, namely enabling schools to serve all children, particularly those with special educational needs.

Organised by the Government of Spain in co-operation with UNESCO, the Conference brought together senior education officials, administrators, policy-makers and specialists, as well as representatives of the United Nations and the Specialised Agencies, other international governmental organizations, non-governmental organizations and donor agencies. The Conference adopted the Salamanca Statement on Principles, Policy and Practice in Special Needs Education and a Framework for Action. These documents are informed by the principle of inclusion, by recognition of the need to work towards "schools for all" - institutions which include everybody, celebrate differences, support learning, and respond to individual needs. They represent an important contribution to the agenda for achieving Education for All and for making schools educationally more effective.

"... Schools should accommodate all children regardless of their physical, intellectual, emotional, social, linguistic or other conditions." (Article 3, Salamanca Framework for Action).

"Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building and inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system." (Article 2, Salamanca Statement).

UNESCO's action in the field of inclusive education has been set explicitly within the 'inclusive education' framework adopted at the Salamanca Conference. This framework stems from the Jomtien World Declaration on Education for All (1990) and was reaffirmed in the Dakar Framework for Action (2000):

"… In order to attract and retain children from marginalized and excluded groups, education systems should respond flexibly... Education systems must be inclusive, actively seeking out children who are not enrolled, and responding flexibly to the circumstances and needs of all learners…" (Education for All: Meeting our Collective Commitments. Notes on the Dakar Framework for Action, Para 33).

Inclusive education is an issue which 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 provides continuity and social interaction for all children, disabled or not. As with non-disabled children, children with disability have gifts and weaknesses. The role of the school should be to try to reinforce the abilities of all

children and strengthen/support all children's potential for learning. Equal opportunities means 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.

Inclusive Education: its role and potential for children with disabilities
Inclusive Education (IE) is a relatively new concept. Basically, it means welcoming all children without discrimination into ordinary schools. By this change in attitude to education, differences between people will possibly be seen from a positive perspective. IE works on the premise that the school is better for all when it includes all children in a community, and that teachers become better teachers when they have the responsibility for all children. By assuming that responsibility, teachers become more active, innovative and creative and learn to see the needs of the individual. *(I. Lopez 'Towards Inclusive Education')*

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 family, the community, other sectors all need to be involved from the start.

Inclusive education is primarily about transforming or building an education system which responds to the real diversity of children, whether according to disability, ethnicity, gender, age, HIV status or other type or difference. The focus is on changing the system, not trying to make the child fit a rigid system.

Inclusive education is good for all children, because it results in school improvement and a methodology and curriculum which is child focused.

Finally, inclusive education is more than inclusive schooling; schools are only one part of education which begins in the family and continues throughout life.

(These points are presented in **Disability Overhead 6.2**).

"Kien's classmates bring him to school every day now that he has a wheel chair that they can push. His wheelchair has a small table attached to it. Though he cannot hold a pen, he can see and listen to his teacher. After only two months at school he knew his alphabet. By the end of the school year he was able to read a book and do calculations up to 10. Now he is in second grade. He is especially quick at Maths, often quicker than his classmates, and can read all the lessons in his book fluently. At one time Kien's grandfather considered giving Kien an overdose of sleeping pills to end his useless life. This same grandfather now glows with pride at his grandson's progress, and is moved to tears of joy when he talks about Kien."

From a Mid-Term Review of Inclusive Education Thoung Tin District, Ha Tay Province, Vietnam, Catholic Relief Services, Hanoi.

The **ARC Resource Pack on Education** contains other relevant material on this subject. Also, **Disability Reading 6.1: "Schools for All"**, at the end of this Resource Pack, provides an excellent account of how one country handled the issues of integration and inclusion within their educational system.

TRAINING MATERIALS FOR TOPIC 6

Overhead 6.1: Key Learning Points for Topic 6	Summary of the key learning points
Overhead 6.2: From Exclusion to Inclusion in Education	Lessons learned from Save the Children U.K.
Overhead 6.3: Becoming More Effective Mangers for Change	G.M. Beall, Social Action Model: Eight Principles.
Exercise 6.1: What is Inclusive Education and How Can We Promote It?	An exercise which aims to develop a clearer understanding about IE and to use this in developing action plans
Exercise 6.2: Promoting Desirable Change within Society	An exercise designed to consider ways of encouraging ways to change attitudes in society
Exercise 6.3: Action Planning	Ranking exercise and short questionnaire to enable participants to develop a personal action plan for the future.
Handout 6.1: The Role of Parents' Organisations Within a CBR System	Extract from 'Prejudice and Dignity' by Dr. Einar Helander
Reading 6.1: From "Schools for All"	A description of an integrated education programme in Lesotho, which is run by the MoE and supported by SCF and UN agencies.

Disability

Sample Programmes

Different participants are likely to have different learning needs and priorities. We have divided participants into three broad groups: senior managers, sector co-ordinators and field staff.

Senior managers are those people who have key responsibility for an NGO's operations in a country or region or a UNHCR Section. They will have overall responsibility for strategy and resource allocation within the organisation's policy framework. Senior managers' needs are likely to be best served through briefings.

Sector co-ordinators comprise those people who have responsibility for a particular aspect of their agency's work in a country or region or who have a responsibility for a particular function within an operation, such as for example UNHCR programme, protection or community services officers. Sector co-ordinators are those responsible for translating policy into practice and ensuring that programme budgets reflect the necessary resources to support good practice.

Field staff are those people working in the field who are responsible for implementing the programme activities. They often have considerable front-line experience. Field staff may value the opportunity to develop and practise new skills as well as develop their knowledge and understanding.

Training programmes should be designed with the responsibilities and learning needs of these different groups in mind. If possible, participants from different groups should be trained separately but if this is not possible exercises and input should be selected which will meet the needs of all groups. It may be possible to use different small group exercises to address the needs of each type of participant in a mixed group workshop.

Two types of programme are included in this Resource Pack. The first describes a half day Awareness-Raising Workshop. The programme makes detailed reference to materials from the Resource Pack and describes how a facilitator might use these materials to conduct a session lasting three hours.

The second example is for a full day workshop. It is written in the form of a Session Plan that covers:

- the overall aim of the training session;
- specific learning objectives;
- a description of what will be covered and the sequence to be followed;
- the timing for each part of the session;
- who will take responsibility for the different parts of the programme;

- what inputs and exercises will be used;

- what materials (e.g. handouts, overheads, briefing papers, index cards) will be required;

- what equipment (e.g. flipchart, overhead projector, blackboard, video) is needed.

The purpose and development of session plans are described in detail in the **ARC Facilitator's Toolkit**.

Both programmes are intended as guidance examples only. It is very important that the facilitator should think carefully about the group of participants with whom he or she will be working and devise a programme that takes into account:

- the role and responsibilities of the participants;

- the learning needs of the participants;

- their existing level of knowledge;

- their interest in the subject;

- their willingness to share experience and admit to gaps in their knowledge / skills;

- current / local issues and priorities for the participants;

- the amount of time they have available;

- their position in their organisation.

Any training programme should be devised, if possible, in consultation with the intended participants. If it is not possible to consult with all participants (for example, by sending out an application form including questions about their expectations for the training), the facilitator should try to speak to a sample of participants before making final decisions about the programme.

The facilitator should also consider:

- the range of Topics to be covered;

- the order in which Topics should be addressed;

- how to encourage the sharing of experience and information between participants;

- who will carry out the training;

- what methods will be most appropriate for the participants.

More detail on the process of training can be found in the **ARC Facilitator's Toolkit**.

Remember to build in a workshop evaluation - you will find ideas for this in the **ARC Facilitator's Toolkit**.

DETAILED PROGRAMME FOR A HALF DAY AWARENESS WORKSHOP

This programme proposes a session of four hours designed to provide participants with an overall awareness of the subject and an introduction to some of the key issues.

LEARNING OBJECTIVES

By the end of this workshop, participants will be able to:

- reach a consensus understanding of what the term "disability" means through a process of analysing attitudes towards disability;

- explain what legislation exists to address the issue of children and adolescents with disabilities;

- describe the different models of disability and their relative strengths and weaknesses;

- describe, in general terms, why children with disabilities are excluded;

- explain why disability is an important issue despite the fact that it is neither very visible or fashionable;

- develop an action plan to improve the situation for children and adolescents with disabilities.

PREPARATION

The facilitator should prepare an information pack for the participants which may include:

- copies of the relevant Handouts and Briefing Notes;

- a copy of the Reading List and relevant Readings;

- copies of relevant materials from the region / country / locality (e.g. research papers, monitoring reports).

If possible, this pack should be sent to participants in advance.

The facilitator should gather any locally relevant information on the Topics to be addressed in the training and identify individuals with specific expertise who could act as resource persons. All participants can be asked to bring along relevant material to display / share with others. The facilitator could, if possible, devise locally appropriate case-studies.

The facilitator should study the notes for each Exercise carefully to ensure that all the necessary materials are prepared in advance.

Introduction – Disability

_____

5 mins	Introduce the agreed objectives of the workshop on Disability on a prepared flipchart. Using **Overhead 1.0 Key Concepts** introduce the relevant Key Concepts.	Flipchart summarising objectives. Overhead 1.0

Definitions of Disability

_____

10 mins	Using briefing notes for **Topic 1**, explain how the term 'Disability' depends on cultural, gender and other prevailing attitudes. Introduce definitions of disability using **Overheads 1.3**, **1.4** and **1.5**.	Overheads 1.3, 1.4 and 1.5
20 mins	Introduce participants to **Exercise 1.2**. It is most important that the criteria for defining Disability are clear and agreed by all. These should be visible to all throughout the whole session.	Exercise 1.2

Legislation and Disability

_____

15 mins	Using Briefing notes from **Topic 3**, introduce the legal framework regarding children with disabilities.	
30 mins	Divide participants into groups of 3 or 5 and ask the groups to work through the **Exercise 3.1**. Distribute copies of the participants' notes Plenary. Summarise responses on flip chart	Exercise 3.1 Participants' Notes

Different Approaches to Disability

_____

5 min	Provide a short introduction to the models of disability and strategies, based on the information provided in **Topic 4** briefing notes. Conduct a brief question and answer session.	Overheads 4.1 and 4.2
30 mins	Introduce **Exercise 4.1**. Participants work through the questions in small groups.	Exercise 4.1
10 mins	Plenary session, summarised on flip chart.	

Why are Children with Disabilities Excluded?

_____

5 mins	Using briefing notes for **Topic 5**, **Overhead 5.2**, and **Handout 5.2** present a short input on why children are excluded.	Overhead 5.2 Handout 5.2
40 mins	Introduce **Exercise 5.2** and work through it with participants. Although this exercise concentrates on education many of the underlying issues associated with exclusion are the same. In plenary session, summarise the outcomes from each group discussion on flip chart paper.	Exercise 5.2 Pre-prepared questions on flip chart

Proposals for Improving the Situation for Children with Disabilities

_____

15 mins	Lead a discussion with the participants, based on **Exercise 6.3, Part 1**, about which principles described would be the most effective in influencing change in terms of the participants' own experience. Note that these principles are also presented in **Overhead 6.3**.	Exercise 6.3 Overhead 6.3
30 mins	Introduce the questions presented in **Part Two** of **Exercise 6.3**. Working in pairs, participants should draw up three proposals each for improving the situation for children and adolescents with disabilities in their personal work situation, that they can take forward into a future work plan.	Exercise 6.3

Summary and Evaluation

_____

10 mins	Review with participants the learning objectives of this session on Disability. Conduct a brief evaluation using forms which you can customise from the **ARC Facilitator's Toolkit**.	Evaluation Forms

TRAINING PLAN FOR A DAY WORKSHOP ON DISABILITY/ WORKING WITH CHILDREN

This programme has been written as a training plan to demonstrate how materials from more than one Resource Pack can be combined to create a workshop which is customised to the needs of a particular group of participants. It is intended as an example only.

OVERALL AIM

The workshop aims to address negative attitudes towards disability and to encourage participants to seek more specific knowledge, so as to ensure that all children and adolescents, including those with disabilities, have access to their basic needs and that they are able to exercise their rights.

LEARNING OBJECTIVES

By the end of this workshop, participants will be able to:

- identify cultural factors in communicating with children in general, and understand their impact on effective communication;

- draw on their own childhood experiences in order to identify key qualities and skills needed to work with children;

- explore their own attitudes to Disability;

- agree on a working definition of the term "disability" within their own working contexts;

- devise possible strategies for facilitating self expression in children;

- describe the different approaches to Disability, and apply this understanding to an analysis of their own working situations;

- reflect on the way that children with disabilities as perceived and treated in an area of Nepal (through a case study) and consider how some of these ideas could be applied to their own working situations;

- describe the role of schools in promoting psycho-social well being for all children and adolescents;

- apply this understanding to the issues surrounding children with disabilities and analyse their ability to attend school;

- consolidate their understanding of Disability issues in the context of their own work and to develop an action plan to improve the situation for children and adolescents with disabilities.

Action for the Rights of Children (ARC)

Timing	Content	Methods	Material	Resources and Equipment	Responsibility
10 mins	**Introduction**	Short input by facilitator.	Disability Overhead 1.0: Key Concepts	Overhead projector Flipchart and pens.	
25 mins	**Disability – Attitudes and Definitions**	Short input by facilitator using material from **Disability Topic 1**.	Disability Exercise 1.4	Flipchart and pens Index cards	
50 mins	**The Importance of Communication - The CRC**	Using **WWC Topic 1** briefing notes, provide an introduction to the importance of communicating with children. Small group exercise with plenary session highlighting importance of the CRC to children with physical and mental disabilities.	WWC Exercise 1.1	Flipchart and pens.	
15 mins	**SUGGESTED BREAK**				
60 mins	**The Importance of Communication – Promoting Coping Mechanisms**	Using **Disability Topic 2** briefing notes, highlight the situation of children with disabilities affected by armed conflict and displacement. Highlight the importance of communication at various levels using a small group exercise.	Disability Exercise 2.1		

45 mins	**Identifying and Communicating with Distressed Children**	Short input by facilitator using Briefing Notes from **WWC Topic 3**. Small group exercise. Guided plenary discussion looking at the implications of this information on children with physical and mental disabilities.	WWC Overhead 3.1 WWC Exercise 3.5	Overhead projector Flipchart and pens.
	SUGGESTED BREAK			
70 mins	**The Role of Schools in Promoting Psycho-social Well-Being**	Short input by facilitator using Briefing Notes from **WWC Topic 5**. Small group exercise.	WWC Exercise 5.3	SWOC analysis framework Flip chart and pens
60 mins	**Why children with Disabilities are Excluded from Schools**	Using **Disability Topic 5 and Topic 6**, highlight reasons why children with disabilities are excluded from education. Small group exercise.	Disability Exercise 5.2 Disability Handout 5.2 Disability Overhead 5.2	Overhead projector Flipchart and pens.
15 mins	**SUGGESTED BREAK**			
60 mins	**Action-planning**	Short input by facilitator, drawing together the points made throughout the day. Small group exercise.	Disability Exercise 6.3 Disability Overhead 6.3	Overhead projector
15 mins	**Workshop Evaluation**	Short input by facilitator. Evaluation exercise.	Evaluation form.	Overhead projector Flipchart and pens.

Disability

Overheads

Disability – Overhead 1.0

Key Concepts

1. Disability is part of human life, and children with disabilities can be found in every society, every culture and every community throughout the world.

2. Attitudes towards people with disabilities vary among different cultures and religions, likewise the notion of what is meant by disability. These prevailing attitudes dictate the level to which children with disabilities are included or excluded from society.

3. The needs of children with disabilities are basically the same as those of other children, but in situations of conflict and displacement it becomes more difficult to ensure that these needs are met.

4. Children with disabilities enjoy equal rights with all other children.

5. Analysis of the individual/medical and social models of disability can be useful in understanding underlying attitudes, and in informing effective approaches.

6. Guiding principles of any approach should be sound communication and participation.

7. Excluding children from activities prevents access to the very support they need for their development.

8. There are a number of ways of encouraging changes of attitudes towards disability and promoting inclusion.

Disability – Overhead 1.1

Key Learning Points for Topic 1

- Prevailing attitudes towards disability largely dictate how excluded a child with disabilities will become within his or her society.

- We need to acknowledge and understand our own attitudes towards disability before setting out to work with this issue.

- The term disability is not a universal concept and varies according to culture, gender, individual and prevailing attitudes within society(ies).

Disability – Overhead 1.2

Disability is a Major Feature of Life

"Disability is a major feature of life and can affect anybody at any time. Disability is not a separate issue from which we can choose to remain detached."

Peter Coleridge:

Disability, Liberation and Development

WHO - Definitions

Functioning refers to all body functions, activities and participation as an umbrella term.

Disability serves as an umbrella term for impairments, activity limitations or participation restrictions.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations.

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

Disability – Overhead 1.4

UN Standard Rules on the Equalisation of Opportunities - Definition of Disability

Disability: "summarises a great number of different functional limitations occurring in any population in any country of the world.

People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness.

Such impairments, conditions or illnesses may be permanent or transitory in nature".

Definition of Disability - Dr. Einar Helander

A disabled person is someone who in his/her society is regarded as disabled, because of a difference in appearance and behaviour.

Disability – Overhead 2.1

Key Learning Points for Topic 2

- In extreme situations, such as war, flight from war, or displacement, the plight of children with disabilities becomes much harder.

- The needs of children with disabilities are basically the same as those of other children, but in situations of conflict and displacement it becomes more difficult to ensure that these needs are met.

- One of the results of conflict situations is an increase in the number of boys and girls with physical or mental impairments.

- The situation of children with disabilities in times of conflict needs to be explored further. There needs to be more knowledge about how they, their families and their communities cope with disability in different settings.

Disability – Overhead 3.1

Key Learning Points for Topic 3

- There are a number of legal standards providing for the effective protection, development and inclusion of children with disabilities.

- Children with disabilities enjoy equal rights with all other children, as set forth in the Convention on the Rights of the Child. They also have specific rights.

- The purpose of the UN Standard Rules is to ensure that girls, boys, women and men with disabilities exercise the same rights and obligation as others (the principle of equality of rights).
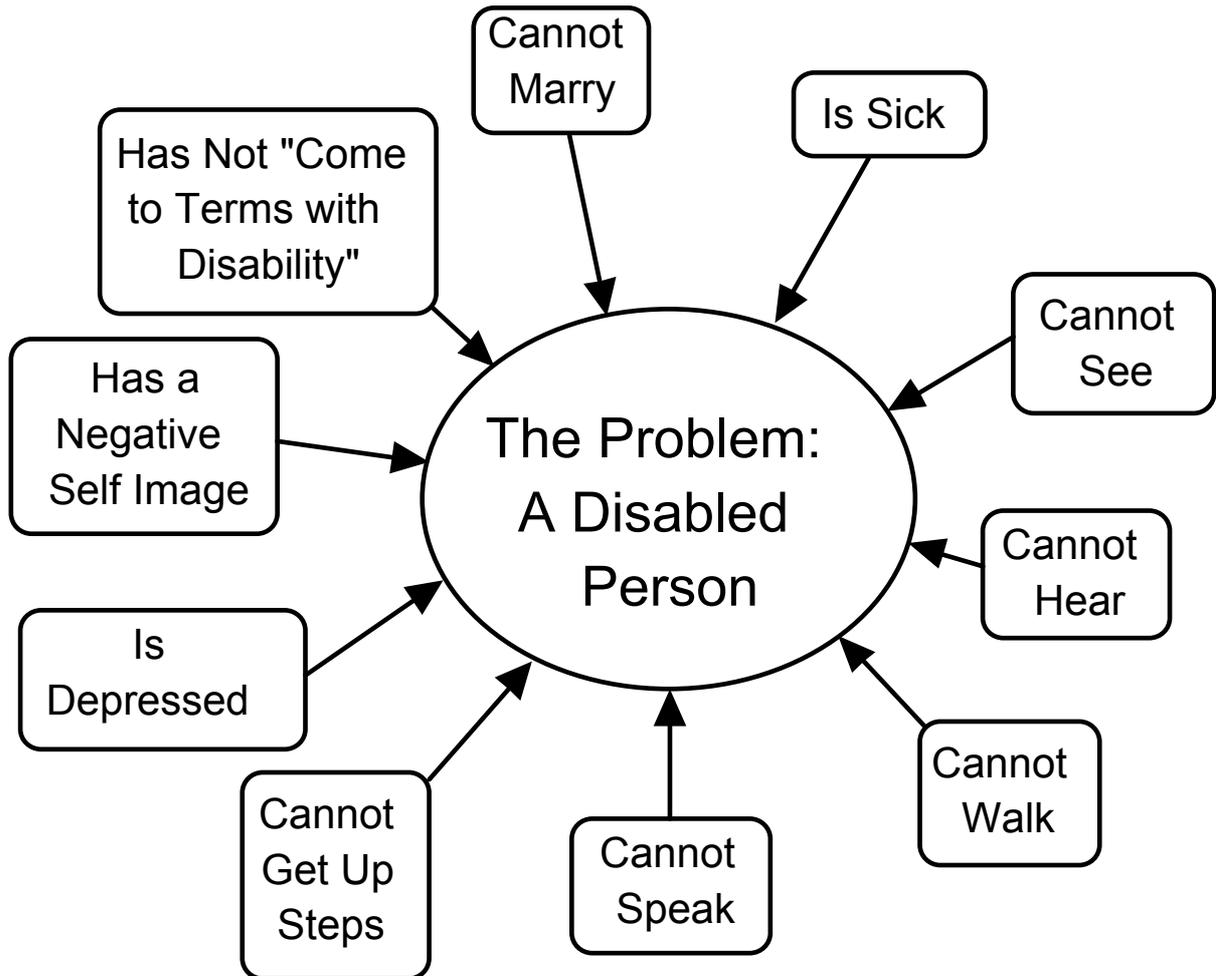
Disability – Overhead 4.1

Key Learning Points for Topic 4

- Analysis of disability models can inform effective approaches.

- Various strategies exist but every situation is likely to be different, and so specific approaches must be adjusted accordingly.

- Sound COMMUNICATION with, and PARTICIPATION of, children with disability and their families will be essential.

- Children and adolescents with disabilities are likely to be disadvantaged on multiple levels and so close cross-sector approaches are necessary.

Disability – Overhead 4.2

The Individual/Medical Model of Disability

Cannot Marry

Is Sick

Has Not "Come to Terms with Disability"

Cannot See

Has a Negative Self Image

The Problem: A Disabled Person

Cannot Hear

Is Depressed

Cannot Walk

Cannot Get Up Steps

Cannot Speak

Disability – Overhead 4.3

The Social Model of Disability

Inaccessible
Buildings

No Jobs

Society Has Not
"Come to Terms"
with the Needs of
Disabled People

Low
Income

The Problem:
A Disabling
World

Inaccessible
Transport

Negative
Attitudes

No
Braille
Books

No Sign
Language
Interpreter

Unrealistic
Expectations
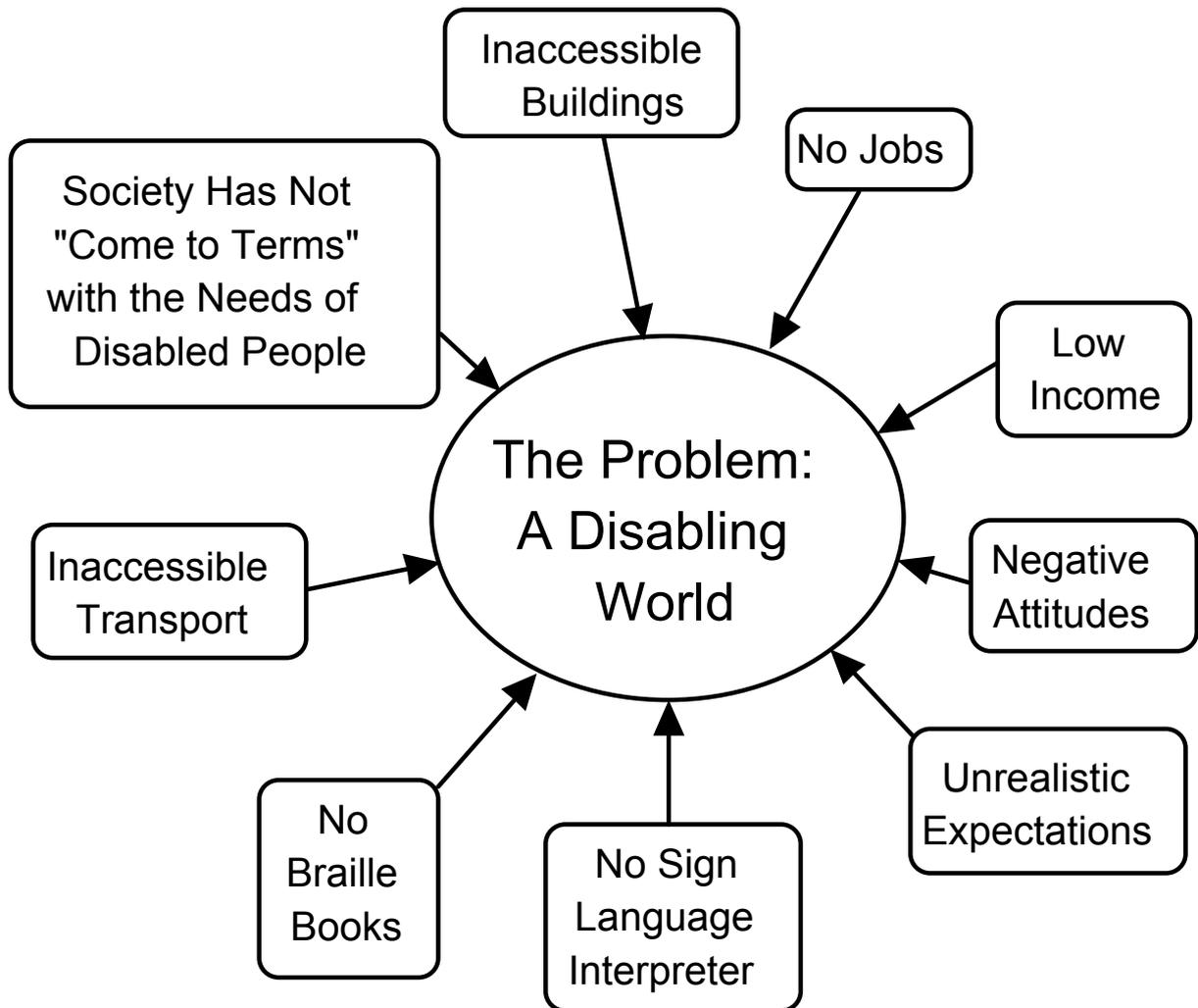
Disability – Overhead 5.1

Key Learning Points for Topic 5

- The reasons why boys and girls with disabilities are often excluded lies with prevailing attitudes and lack of understanding in society as a whole.

- From policy development, through planning and design, and on to implementation the views of children are rarely taken into account.

- Children with disabilities are not one homogenous group. Like all boys and girls they are all different individuals with differing needs.

- From birth, children with disabilities can be excluded from accessing the very support they need for their development.

Factors Influencing the Extent to which a Child with Disabilities is Excluded

- Ignorance, attitudes, false beliefs are the main barriers in all cultures.

- Gender: girls with disability more likely to be discriminated against.

- Children in difficult circumstances are especially vulnerable to exclusion, largely due to exclusive policy making and implementation.

- Poverty: families with disabled members are frequently the poorest and most marginalised.

Key Learning Points for Topic 6

- There are a number of ways of encouraging changes of attitudes towards disability and promoting inclusion.

- Attending school provides continuity, creates a sense of normality and promotes social interaction for all children, with disabilities or not.

- Inclusive education is primarily about transforming or building an education system which responds to the real diversity of children.

- The role of the school should be to reinforce the abilities of all children and support all children's potential for learning.

- Education is a basic right and, contrary to common belief, making education inclusive can improve access and quality for all.

Disability – Overhead 6.2

From Exclusion to Inclusion in Education: Lessons Learned from Save the Children UK

- Inclusive education is part of a strategy for inclusive development; it cannot take place in isolation. The family, the community, other sectors all need to be involved from the start.

- Inclusive education is primarily about transforming or building an education system which responds to the real diversity of children, whether according to disability, ethnicity, gender, age, HIV status or other type or difference. The focus is on changing the system, not trying to make the child fit a rigid system

- Inclusive education is good for 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.

Becoming More Effective Managers for Change (G.M.Beale: Social Action Model)

- Recognise and understand the existing social situation

- Define the underlying problem

- Locate relevant groups and institutions which may be used to bring about change

- Communicate with the influential people in the area informing them what you are trying to do, and enlist their support

- Diffuse information so that everyone knows exactly what you want to do and why, and also how you intend to do it

- Obtain a commitment to action from involved persons (parents, teachers.)

- Define aims and objectives so that people can see where they are supposed to be going and when they should expect to get there.

Disability

Exercises

1.1	Exploring Attitudes Towards Disability	Senior Managers, Sector Co-ordinators, Field Staff.
1.2	Exploring Attitudes Towards Disability: Relational Attitude Scale	Senior Managers, Sector Co-ordinators, Field Staff.
1.3	What Does "Disability" Mean?	Senior Managers, Sector Co-ordinators, Field Staff.
1.4	Who is Disabled?	Senior Managers, Sector Co-ordinators, Field Staff.
2.1	Promoting Coping Skills for Disabled Children Affected by Conflict	Sector Co-ordinators, Field Staff.
2.2	Considering the Effective Use of Surveys	Sector Co-ordinators, Field Staff.
3.1	Needs and Rights Exercise	Sector Co-ordinators, Field Staff.
3.2	Children with Disabilities and Their Rights	Senior Managers, Sector Co-ordinators.
4.1	Looking at Different Approaches to Disability	Senior Managers, Sector Co-ordinators, Field Staff.
4.2	Different Approaches to Disability - Case Study from Nepal	Field Staff.
5.1	Considering Excluded Children – Case Study from South Lebanon	Field Staff.
5.2	Why are Children with Disabilities Excluded from Primary School?	Sector Co-ordinators, Field Staff.
6.1	What is Inclusive Education and How Can We Promote it?	Sector Co-ordinators, and Field Staff.
6.2	Promoting Desirable Change in Society	Sector Co-ordinators, Field Staff.

6.3	Action Planning	Senior Managers, Sector Co-ordinators, Field Staff.

Disability

Exercise 1.1
Exploring Attitudes towards Disability

TARGET GROUP

Senior Managers, Sector Co-ordinators, Field Staff.

OBJECTIVES

By the end of this exercise, participants will be able to:

- recognise the many different attitudes towards disability;

- acknowledge their own attitudes towards disability.

TIMEFRAME

15 - 20 minutes

METHOD

Devise four statements about children with disability (using your own judgement about what sort of statements might be relevant to each particular training group) and pin them up in different parts of the room:

For example, these statements could be about inclusion in school:

Children with disability need to go to special schools.

Children with disability should go to special classes with children with the same type of disability.

Children with disability should go to the school where the other kids are going in the neighbourhood.

Children with disability should be taught at home…

Or statements with direct connection with a particular situation:

We don't have time to screen for disabilities during registration.

We can not 'care' for the disabled now - we are dealing with food shortage.

The playgroup is already overcrowded - we can not have disabled children too.

We have found 30 disabled children and we have referred them to the clinic - so we do not need to count them for the school activities...

Invite participants to stand beside the statement that they most agree with. Ask participants who find themselves beside the same statements to discuss why they chose that particular statement. Then ask participants to talk to others who chose different statements and to discuss reasons why they chose those statements.

Facilitate short discussion on differing attitudes to disability using the **Briefing Notes for Topic 1.**

Encourage participants to reflect, in their group, on situations where they have seen children with disability and what they thought about it.

RESOURCES

Four statements prepared on flip chart paper by the facilitator.

Blue tack or pins for attaching to the wall.

Disability

Exercise 1.2: (Facilitator's Notes)
Exploring Attitudes Towards Disability: Relational Attitude Scale

TARGET GROUP

Senior Managers, Sector Co-ordinators, Field Staff.

OBJECTIVE

By the end of this exercise, participants will be able to:

- acknowledge and explain their attitudes towards disability to others.

TIMEFRAME

Up to 30 minutes, depending on the diversity of the participants.

METHOD

Divide participants into groups of 4 or 5. Give to each participant one copy of the Participants' Notes for this exercise plus an extra copy for the group. Ask groups to follow the instructions at the top of the page and, having completed the task, to discuss their differing viewpoints. It is important to emphasise that there are no right or wrong answers in this exercise. Organise a brief feedback session when the group discussions come to an end.

RESOURCES

Copy of **Participants' Notes** for each participant.

One extra copy for each group to assist group leader in discussions.

Disability

Exercise 1.2: (Participants' Notes)
Exploring Attitudes towards Disability: Relational Attitude scale

OBJECTIVE

By the end of this exercise, you will be able to:

• acknowledge and describe your attitudes towards disability with others in a small group situation.

TIMEFRAME

Up to 30 minutes, depending on the diversity of the participants.

METHOD

You are invited to work in groups of 4 or 5. Please work through the **Relational Attitude Scale** on your own in the first instance, deciding for each statement how much you agree or disagree with it and marking it accordingly (e.g. if you strongly agree, circle 1; if you strongly disagree circle 5). When your group has completed this task, nominate one member as "group leader". This person should then read out the statements one by one and take note of the group's reaction to each statement on the extra copy provided. Where there are big differences of opinion, these should be discussed briefly within the group.

REMEMBER: THERE ARE NO RIGHT OR WRONG ANSWERS.

RELATIONAL ATTITUDE SCALE:

		Strongly agree			strongly disagree	
1.	Disabled children should be kept away from other children in school	1	2	3	4	5
2.	There should be some reserved seats for the disabled on public transportation	1	2	3	4	5
3.	Disabled employees should be treated like any other employees	1	2	3	4	5
4.	Disability should not be a consideration in marriage	1	2	3	4	5
5.	Disabled people should participate like everyone else in social activities	1	2	3	4	5
6.	Disabled children should study in regular school without any discrimination	1	2	3	4	5
7.	There should be separate transportation for the disabled	1	2	3	4	5
8.	Disabled employees should have separate workspaces in an organisation	1	2	3	4	5
9.	A disabled person should only marry another disabled person	1	2	3	4	5
10.	Disabled people should mostly stay at home	1	2	3	4	5
11.	There should be special separate schools for the disabled	1	2	3	4	5
12.	Everyone should use the same transportation - of course disabled people should be given some assistance if needed	1	2	3	4	5
13.	Disabled people should normally work at home	1	2	3	4	5
14.	Normally, people with disability should not marry	1	2	3	4	5
15.	There should be separate social activities for the disabled	1	2	3	4	5
16.	Non disabled children should also join special schools for the disabled	1	2	3	4	5
17.	It should be left to disabled people themselves to decide on their mode of transport	1	2	3	4	5
18.	Some categories of jobs should be reserved for the disabled in every organisation	1	2	3	4	5
19.	Marriages between disabled and non-disabled people should be encouraged	1	2	3	4	5
20.	Disabled persons should be specially invited to social celebrations	1	2	3	4	5

Disability

Exercise 1.3:
What Does "Disability" Mean?

TARGET GROUP

Senior Managers, Sector Co-ordinators, Field Staff.

OBJECTIVES

By the end of this exercise, participants will be able to:

- describe their own attitudes towards disability by being part of a process which defines and redefines the term;

- reach a consensus decision about what the term "disability" means;

- describe generally accepted definitions of "disability" and come to a consensus of what definitions are relevant in the context of the group's work and experience.

TIMEFRAME

30 minutes.

METHOD

Distribute a blank card (card 1) to each of the participants; ask them to write down what the term "disability" means. Emphasise that there should be no sharing of ideas at this point. When all the participants have written a definition, invite them to find a partner. Give each pair a new blank card (card 2). In pairs, participants should share their ideas and write a revised definition of "disability". When card 2 (the revised definition) has been written, invite pairs to join with another pair, thus working in groups of four. Distribute another blank card (card 3) per group. Repeat the process using the definitions developed on card 2, to further revise the definition of "disability".

Continue with the revision process until the whole group agree on a definition of "disability". Write the group definition of "disability" on a flip chart.

Lead short plenary session on comparing the group definition of "disability" with other accepted definitions (see Disability Overheads 1.3, 1.4 and 1.5). Encourage participants to look back to their original and individual definition and to think about how and why it differs from the later versions.

RESOURCES

Sets of blank cards, titled **Card 1, Card 2, Card 3** (see above).

Flip chart paper and pens.

Disability Overheads 1.3, 1.4 and 1.5.

Disability

Exercise 1.4:
Who is Disabled?

TARGET GROUP

Senior Managers, Sector Co-ordinators, Field Staff.

OBJECTIVE

By the end of this exercise, participants will be able to:

- explain what is "disabling" about different situations and conditions.

TIMEFRAME

15 minutes.

METHOD

Before the training session, prepare the following statements either on flip chart or sets of cards (one set of cards will be required for each small group)

- **A girl has difficulty in moving. She goes to school and she plays with her friends, but she needs help to get to school.**

- **A boy has hearing difficulties. He is outside the whole day and, according to his mother, is always being "naughty". She says that he doesn't do what she tells him.**

- **A girl stays at home most of the time. She cannot walk. At home she helps her older sister in the house.**

- **A boy does not play with other children because his behaviour is different. His father and mother feel embarrassed and they are trying to keep him at home. In the past, they sent him to school, but they were discouraged by the teachers who described him as a "hopeless child".**

N.B. The facilitator can either use the situations above or devise other ones that might be more appropriate to the participants' own experience and situations.

Divide the participants into small groups (3 - 5). Ask each group to read the four situations described and to consider the following questions:

- **Which children are disabled? Which are not disabled?**

- **Of the children that you consider to be disabled: Why are they disabled?**

- **What criteria did you use to define who is disabled?**

Short plenary session: brief feedback from each group and highlight the key points to emerge on flip chart. The most important part of this exercise is to define and agree criteria for the term "disabled".

RESOURCES

Prepared copies of the situations and the questions, either on cards or on flip chart.

Flip chart paper.

Disability

Exercise 2.1: (Facilitator's Notes)
Promoting Coping Mechanisms for Disabled Children Affected by Conflict

TARGET GROUP

Sector Co-ordinators, Field Staff.

OBJECTIVES

By the end of this exercise, participants will be able to:

- describe coping mechanisms for disabled children in armed conflict and displacement situations;

- identify ways of supporting disabled children in such situations.

TIME FRAME

45 minutes

METHOD

Note: Ideally, participants should be given the article "Violence and Disabled Children" by Naomi Richman (**Disability Reading 2.1**) to read before the start of this exercise. Otherwise, the facilitator should make a short presentation based on this paper. The Participants' Notes include the final part of the article.

Introduce the subject of armed conflict and the situation for disabled people under these circumstances. Ask participants to read the **Participants' Notes** for this exercise and, working in small groups to diamond rank (see **ARC Facilitator's Toolkit** for a description of this method) the coping mechanisms discussed, in their perceived order of priority, and based on their own experiences.

The facilitator may find it easier to prepare for this exercise by making sets of cards where each coping skill described in the article is written on a separate card and a complete set of cards is prepared for each group. Ask each group to add to the list of coping skills, based on their own ideas and experience.

Short plenary where new ideas are written up (on flip chart).

RESOURCES

Copies of **Disability Reading 2.1** and **Participants' Notes** for each participant.

Prepared cards for **Ranking Exercise**.

Flip chart paper.

Disability

Exercise 2.1: (Participants' Notes)
Promoting Coping Mechanisms for Disabled Children Affected by Conflict

OBJECTIVES

By the end of this exercise, you will be able to:

- describe coping mechanisms for disabled children in armed conflict and displacement situations;

- identify ways of supporting disabled children in such situations.

TIME FRAME

45 minutes

METHOD

You are invited to read the following extract from Naomi Richman's article "Violence and Disabled Children".

Promoting Coping Skills

Disabled children affected by conflict need similar support to that required by other children, especially the possibility of a confiding adult.

Information and Participation

Adults are often reluctant to speak with children about their situation or their impairment. This is excused by saying that the child is too young to understand. The child is left with anxieties unexpressed, or lacking essential information, for example about their feelings associated with a phantom limb, or the degree of improvement expected after poliomyelitis.

In busy clinics, especially in conflict situations, no one has responsibility for explaining the condition and possible future help to the child or the family. Indeed, health workers may not be able to speak the child's language, or be familiar with the culture, so the opportunities for essential explanation and follow-up are lost. This communication is particularly important for conditions like leprosy, where often ideas about causation militate against adequate treatment.

Training health advocates, who need not be health workers, could convey these important explanations, and provide information to relatives about how they can help a child with an impairment.

Wherever possible, children should be involved in making decisions themselves, for example, about fitting prosthesis, or about where they are going to live.

Working with the family

In situations of war or in refugee camps, it is not easy to initiate programmes of support for disabled children, but it is important to do as much as possible, otherwise valuable time is lost, during which the child should be learning and developing. Discussions with local communities may bring up useful ideas about what would be feasible.

Most families are very pleased to have the possibility of help providing that it is relevant to their needs: for example, a day centre so that mothers can work; physiotherapy advice; and practical aids, exercises or occupation for a child. At the very least, discussions could aim at encouraging adults to communicate with children about their situation, and ensure their integration and participation in the wider community, particularly if schooling is available.

A variety of initiatives have been described for supporting women affected by conflict, especially those with children. These include involving mothers in group discussions or activities such as setting up and running pre-school centres (Fozzard and Tembo 1993). In this way the morale of the mothers is raised and they are more able to respond to the needs of their children.

Promoting integration

Wherever possible, disabled children should be involved in normal activities with other children. 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 disabled children, and ensure they are not marginalised, and that their capacities and special 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 focussed on understanding other people's feelings and needs, could be used to promote integration of disabled people.

Make a list of the different suggestions for promoting coping skills that emerge from this article.

Rank the list in order of which skills you consider to be most useful.

Add any other skills to the list that come from your own ideas and experience.

Disability

Exercise 2.2: (Facilitator's Notes)
Considering the Effective Use of Surveys

TARGET GROUP

Sector Co-ordinators, Field Staff.

OBJECTIVES

By the end of this exercise, participants will be able to:

- assess the usefulness of surveys in terms of identifying people with disabilities and understanding their needs;

- describe the characteristics of useful surveys and how best to use them.

TIMEFRAME

45 minutes

METHOD

Introduce the topic by discussing surveys with the participants: what they are used for and at what stages; what they tend to identify, and what they fail to identify. Present and distribute copies of **Handout 2.1**.

Participants could be invited to share their experiences on the pros and cons of using surveys generally. Introduce the idea that people with disabilities criticise the use of surveys, and offer reasons why (refer to **Briefing Notes for Topic 2**).

Participants to work in small groups using the **Participants' Notes** for this exercise. They will need flip chart paper to record their suggestions.

Plenary session to draw together all suggestions for surveys which serve to better highlight the needs and rights of children and adolescents with disabilities.

RESOURCES

Copy of **Participants' Notes** for each participant.

Copy of **Handout 2.1** for each participant.

Flipchart paper.

Disability

Exercise 2.2: (Participants' Notes)
Considering the Effective Use of Surveys

OBJECTIVES

By the end of this exercise, you will be able to:

- assess the usefulness of surveys in terms of identifying people with disabilities and understanding their needs;

- describe the characteristics of useful surveys and how best to use them.

TIMEFRAME

45 minutes

METHOD

You are invited to read the following text:

There is an obvious need to find vulnerable children in a refugee camp so as to secure their rights and initiate activities so that their needs are met as far as possible. It is a known fact that disabled boys and girls often are forgotten about in these situations. Some of the most crucial protection issues may relate to situations, which cannot be easily seen or understood. Hence, the importance of systematic surveys and situation analysis.

When considering the development of surveys, which would provide useful information about vulnerable children, it is worth thinking about what sort of questions would be most useful to improving the situation of the children themselves. For example, asking questions that directly 'segregate' disabled children may lead to these children being isolated; basing questions on *types* of disability may be confusing, as perceptions of disability vary according to culture and attitudes. It might be more appropriate to start the questioning process along the following lines:

- Which children are not attending the clinic?

- Which children are not joining in some or any of the planned activities for children?

- Why aren't they attending/joining in?

- What is the best way of finding answers to these questions?

Follow up work based on the answers to these sorts of questions, particularly if it is carried out by people who are trained in disability awareness, is more likely to lead workers to finding, including and ensuring the rights of disabled children and adolescents.

In your group, discuss answers to the following questions:

In developing or revising a survey that seeks to ensure that more children with disabilities are included (but not targeted as a "special group"):

1. *What information would you seek?*

2. *What sources of information would you use?*

3. *What skills/techniques would you use?*

Disability

Exercise 3.1: (Facilitator's Notes)
Needs and Rights Exercise

TARGET GROUP

Sector Co-ordinators, Field Staff.

OBJECTIVE

By the end of this exercise, participants will be able to:

- explain how the needs and rights of children and adolescents, differ (or not) from those of children with disabilities.

TIMEFRAME

30 minutes

METHOD

Organise participants into small groups (3 - 5 in each) and give a copy of the **Participants' Notes** to each group. Ask them to consider the following questions:

What are the needs of children?

Who is responsible for meeting these needs?

What is the relationship between needs and rights?

Invite each group to present feedback on their discussions. Discuss similarities and differences and how the groups reached their conclusions.

Try to reach a consensus/conclusion on what needs and rights are: one way to see it is that children might have different needs at various stages of life, whereas the rights are always the same, you are born with your rights, hence children with disabilities have the same rights as all children, although their needs might be different. The needs constitute a basis for the rights.

Ask the participants to repeat the above activity, but now with these questions:

What are the needs of children with disability?

Who is responsible for meeting these needs?

Analyse in a plenary discussion whether the answers were different from the first discussion and discuss why they were different or similar.

RESOURCES

Copy of **Participants' Notes** for each participant.

Disability

Exercise 3.1: (Participants' Notes)
Needs and Rights Exercise

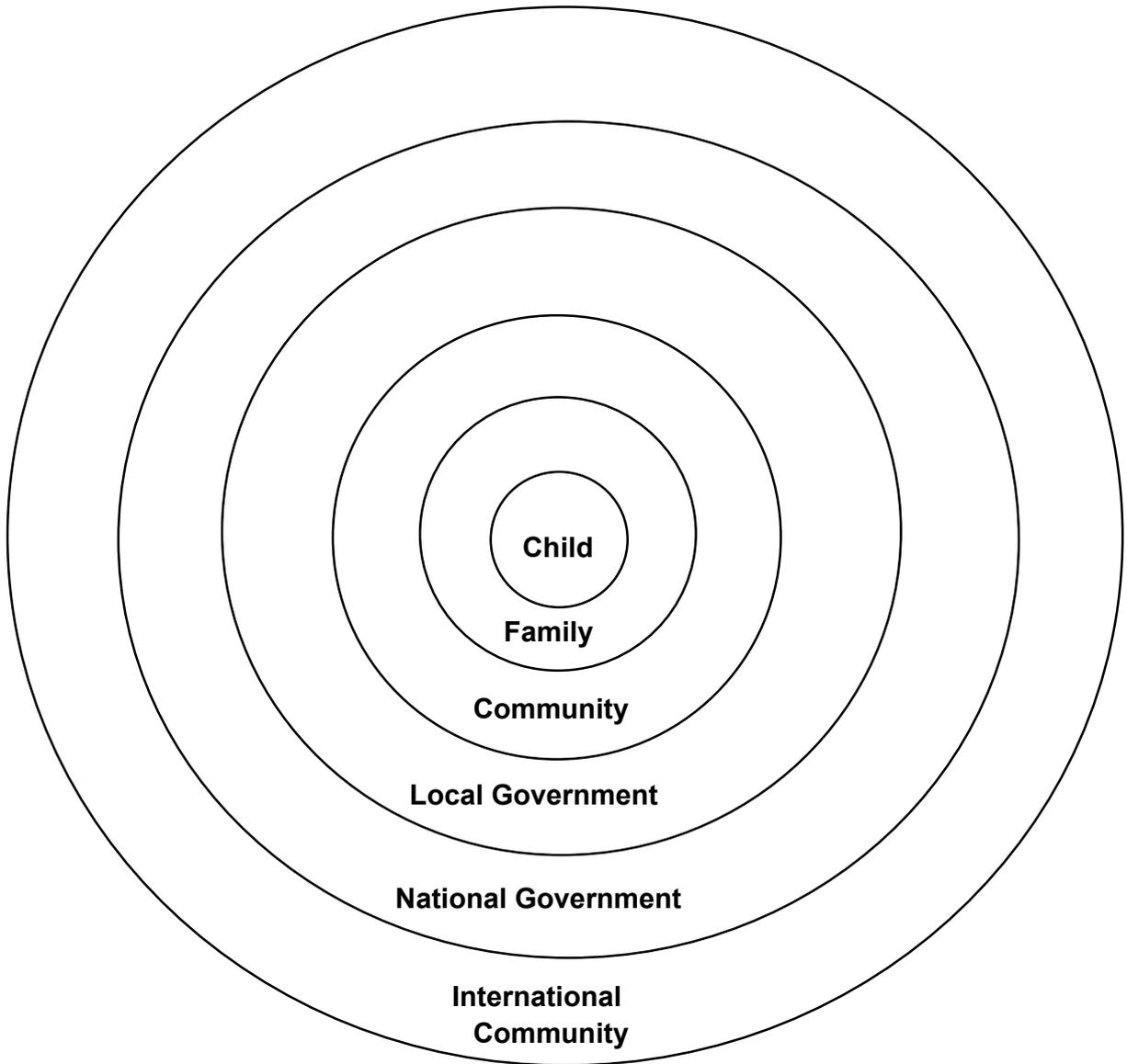**OBJECTIVE**

By the end of this exercise, you will be able to:

- explain how the needs and rights of children and adolescents, differ (or not) from those of children with disabilities.

TIMEFRAME

30 minutes

METHOD

The facilitator will give you questions to accompany this worksheet. Please use this diagram in order to answer question 2: ***Who is responsible for meeting these needs?***

Child

Family

Community

Local Government

National Government

**International
Community**

Disability

Exercise 3.2: (Facilitator's Notes)
Children with Disabilities and Their Rights

TARGET GROUP

Senior Managers, Sector Co-ordinators.

OBJECTIVES

By the end of this exercise, participants will be able to:

- explain how the CRC relates to children and adolescents with disabilities;
- suggest forms of support which would ensure compliance with the Convention in particular cases;
- identify who is responsible for ensuring this compliance.

TIMEFRAME

60 minutes

METHOD

Divide participants into groups of 4 - 5. Distribute copies of the **Participants' Notes** for this exercise and allow 45 minutes for the group work.

Take feedback in plenary and discuss differences and similarities both in the case studies and the responses from the groups of participants.

RESOURCES

Copy of **Participants' Notes** for each participant.

Copies of the CRC full text for the participants to refer to.

Disability

Exercise 3.2: (Participants' Notes)
Children with Disabilities and Their Rights

OBJECTIVES

By the end of this exercise, you will be able to:

- explain how the CRC relates to children and adolescents with disabilities;

- suggest forms of support which would ensure compliance with the Convention in particular cases;

- identify who is responsible for ensuring this compliance.

TIMEFRAME

60 minutes

METHOD

For this exercise, you will need a copy of the CRC in full text.

Read the two case studies below. For each one:

- discuss which articles of the Convention are being contravened or are at risk of being contravened;

- discuss what forms of support could be provided to help ensure compliance with the convention in each of the case studies;

- finally, discuss who should be responsible for providing these various forms of support.

CASE STUDY 1:

Anna, a girl of 10 years, spends most of her day in a dark room at home. She never goes any further than the courtyard of the house. Anna is perceived to be a bit different than others in society and her mother will not let her leave the house.

A year ago Anna's mother took her to school, but the teacher told her that he could not accept her. He did not have any conditions for taking care of her. He also pointed out that she would probably be harassed by the other children, as they would consider her to be different.

A few months after the above incident, a teacher from a neighbouring village visited Anna and her mother. He said she could come to his school. The only problem was that the school was located 15km from Anna's village and her family had no means of paying for transport.

CASE STUDY 2:

Carlos is 11 years old. Every day he goes to the local market to try to earn some money for his family. His two brothers and one sister go to school but Carlos is a bit different and his family don't think it is worth letting him go to school. It is better that he helps his family.

At the market, Carlos helps people carry things and runs errands. Often he is given little or no money as he cannot express himself that well. Sometimes he is also beaten and harassed by customers and sellers and told to leave the market.

Disability

Exercise 4.1:

Looking at Different Approaches to Disability

TARGET GROUP

Senior Managers, Sector Co-ordinators, Field Staff.

OBJECTIVES

By the end of this exercise, participants will be able to:

- describe the main models associated with disability;

- explain the strengths and weaknesses of different approaches;

- apply an understanding of different approaches to their own situation; to look at how they and their organisations approach disability.

TIMEFRAME

45 - 60 minutes

METHOD

Prepare a short presentation on the different models to disability (using the **Briefing Notes for Topic 4**, together with **Overheads 4.2** and **4.3**). Answer any questions arising from the presentation.

Divide participants into small groups (3 - 4 max) and ask them to consider the following questions.

1. What do you consider to be the strengths and weaknesses of the different models?

2. Use an analysis of the models to describe the approach most commonly used by a) you, and, b) your organisation?

Organise a feedback session. Suggestions for developments within organisations, and/or personal, should be taken forward to an action planning session.

It is also possible to do a SWOC Analysis for this exercise (for a description of this method, see **ARC Facilitator's Toolkit**).

RESOURCES

Disability Overheads 4.2 and 4.3.

Flip chart paper.

Disability

Exercise 4.2: (Facilitator's Notes)
Different Approaches to Disability -
Case Study from Nepal

Note: This exercise is normally to be used as a follow-up to **Disability Exercise 4.1**. If, as the facilitator, you would like to use this exercise without having worked through Exercise 4.1 it will be necessary to provide a short presentation on the different models/strategies to disability (using the **Briefing Notes for Topic 4**, together with **Overheads 4.2** and **4.3**)

TARGET GROUP

Field Staff.

OBJECTIVES

By the end of this exercise, participants will be able to:

- describe the way in which children with disabilities are perceived and treated in one area of Nepal;

- assess whether these approaches would work successfully in participants' own work situations.

TIMEFRAME

45 minutes

METHOD

Divide participants into small groups. Distribute copies of the **Participants' Notes** for this **Exercise**.

Ask the participants to consider the following questions:

1. Which models/strategies to disability have been used in this case study?

2. Which aspects of the programme strike you as the most appealing? Why?

3. Discuss which approaches would/would not work in your situation?

Short plenary session.

RESOURCES

Copy of **Participants' Notes** for each participant.

Flip chart paper and pens.

Disability

Exercise 4.2: (Participants' Notes)
Different Approaches to Disability –
Case Study from Nepal

OBJECTIVES

By the end of this exercise, you will be able to:

- describe the way in which children with disabilities are perceived and treated in one area of Nepal;

- assess whether these approaches would work successfully in your own work situations.

TIMEFRAME

45 minutes

METHOD

In small groups, read the case study on the following page and answer the questions at the end:

DISABILITY AND REFUGEES - THE EXAMPLE OF NEPAL.

From reports by Gauri Giri, summarised by Sue Stubbs, June 1997. Notes on an example of good practice in relation to including disabled people in a refugee programme.

The Jhapa Refugee programme is a good example of addressing disability within a refugee context. The following is a summary of the history and key components of the project, which contribute towards its quality, impact and sustainability:

- disabled people were identified from a health review (1994) as part of a particularly vulnerable group whose needs were not being met.

- an inter-agency meeting (1995) established a working group of agencies involved in the social sector to develop a collaborative approach to responding to the needs of disabled people.

- from the start, the approach was collaborative and aimed to be sustainable, integrated within the community, and promoting self-reliance not dependency.

- SCF (UK) agreed to implement a pilot project. This began with a Focus Group Discussion to expose staff to issues and identify future courses of action; participatory approaches and an action-research approach were used from the start.

- The FGD was carried out with disabled children, their parents and SCF staff. The team focussed on children with physical, sensory and speech impairments, so making an effort to look at different types of disability.

- The results of the FGD gave the team information about attitudes, impact on the workload and life styles of mothers; the children spoke about how they helped their parents, but were withdrawn about going outside because they got teased.

- Education was a unanimous priority for both parents and children. Parents were over-protective and their children were not getting opportunities for play and interaction.

- SCF allocated a full time member of staff (who was not previously a disability specialist), recognising that this was important to support the project. This staff member had a strong community development perspective and so was keen not to increase dependency by providing "special" programmes.

- The pilot programme, as a result of the FGD, focussed on home visiting support, referral, integration of children in schools, the orientation of staff and the community. Home visiting systems varied from camp to camp, some were neighbours, and others were teachers and women volunteers. It was felt that the neighbour-to-neighbour support worked best.

- The action research approach continued to be used in order to develop an appropriate and effective programme. The pilot programme was evaluated after six months. The evaluation highlighted good social integration, good parent support, good inter-agency collaboration, and active community participation. But there was a need for more information about helping communication problems, more work on helping parents to be involved in planning rather than just implementing, more awareness raising in the community.

- The programme continues to research and address the issue of attitudes in the

community using multi-media activities; drama, song, story, visual aids - over 700 children have been integrated into mainstream schools, and a pilot integrated pre-school is operating.

- Low cost aids and toys are being produced.

- Sign language training has been conducted in all camps and both hearing and deaf children are actively signing.

- Other issues being addressed are: vocational training opportunities for older children, production of awareness-raising materials, more training for health workers and teachers, day care for children with severe disability.

- Maximum use has been made of national and international resources and contacts; visits have been exchanged with other disability programmes, trainers have visited, resource persons have given input.

To summarise, this programme is an excellent model of an approach to integrating disability with the following criteria of success:

- Participatory, action research approach used from the start, gaining perspectives from consumers: disabled children and parents.

- Focussing on integration by targeting activities and resources: by removing barriers to participation; negative attitudes; over-protectiveness; and developing awareness in the community etc.

- Ensuring sustainability from the start through supporting and involving parents and promoting self-help and self reliance; it would be easier and quicker to establish a "service" without community/parent involvement, but it would just increase passivity and would not provide any useful skill/ownership for the future.

- Balancing practical and visible models with more general advocacy and influence at policy level: e.g. the integrated pre-school met with a lot of resistance from UNHCR, but the model is very successful, and the aim is to promote it in other camps.

- Not focussing on disability as the problem of the individual child, but seeing disability in a broader development and rights context.

- Particular examples of pioneering activities such as sign language training, respecting the mother tongue of deaf children, and developing an appropriate model to improve communication.

- Good management and support at all levels, and good choice of full-time co-ordinator; a disability specialist is not as important as a person with a good understanding of the community and how to involve them.

In small groups, discuss the following questions:

1. Which models/strategies to disability have been used in this case study?

2. Which aspects of the programme strike you as the most appealing? Why?

3. Discuss which approaches would/would not work in your situation?

Your facilitator will invite feedback from your discussion in a plenary session.

Disability

Exercise 5.1: (Facilitator's Notes)
Considering Excluded Children - Case Study from South Lebanon

TARGET GROUP

Field Staff.

OBJECTIVE

By the end of this exercise, participants will be able to:

- describe how best to address the issue of excluded children in their own work situations.

TIMEFRAME

45 – 60 minutes

METHOD

Divide participants into groups of 3 or 4. Give each participant a copy of the **Participants' Notes** for this exercise. Ask the participants to read the case example and discuss the questions in their groups. Allow 20 minutes for this part of the exercise. There is no need for a plenary at this point, but spend some time with each group. Be prepared to pick up on any important experiences that individual participants might wish to share.

Using the following set of questions (pre-prepared on flip chart) ask participants to stay in the same groups, and to discuss and answer these questions:

1. **Are there children with disabilities in your community?**

2. **How does their community treat them?**

3. **Are there any differences in between girls and boys?**

4. **Are there differences in how well they are integrated according to sex, age and type of disability?**

5. **Who are the children most discriminated against in your community?**

Close the session with a short plenary session, highlighting the main outcomes.

RESOURCES

Copy of **Participants' Notes** for each participant.

Flip chart paper and questions prepared on flip chart.

Disability

Exercise 5.1: (Participants' Notes)
Considering Excluded Children: Case Study from South Lebanon

OBJECTIVE

By the end of this exercise, you will be able to:

- describe how best to address the issue of excluded children in your own work situations.

TIMEFRAME

45 minutes

METHOD

You are invited to read the following case study and (in small groups) consider the questions at the end of the text.

The facilitator will have a further set of questions for you to consider when you have finished this task.

Case from the book *Gender and Disability*: Lina Abu-Habib, OXFAM:

During the summer of 1993, there was a major Israeli military offensive in South Lebanon which caused hundreds of casualties and massive exodus and displacements. The Lebanese Sitting Handicapped Association (LSHA) along with eight other local NGOs was involved in relief and emergency work. LSHA was surveying damages suffered by disabled persons and their families, as well as cases of new injuries. On arriving in the village, they asked as usual for the co-operation of the villagers in surveying the houses. Knowing that LSHA is an association of disabled persons, a woman approached them and told them that she knew of a next-door neighbour who had a disabled daughter, now a teen-ager. However she had not seen her for a long time, and certainly not after the military offensive. She was concerned because a mortar shell had directly hit their house. On entering the half-destroyed house, LSHA volunteers discovered the girl inside, injured in a pitiful state. An investigation revealed that when the family fled the village, her father refused to take her, leaving her under the fire and perhaps hoping that she would be killed, and this would be 'God's wish'. He also told LSHA volunteers that he had preferred to save their cow because she is more useful to them than their disabled daughter. When LSHA wanted to take the girl to a nearby hospital for her wound to be treated, her father refused.

1. **Have any of you experienced anything similar to this in your work? Share your experiences with the other members of your group.**

2. **The father seems to be a cruel person in this story - what could the reason be?**

3. **What would you do if you were working in this situation and you had just heard this story?**

Disability

Exercise 5.2: (Facilitator's Notes)
Why are Children with Disabilities Excluded from Primary School?

TARGET GROUP

Sector Co-ordinators, Field Staff.

OBJECTIVES

By the end of this exercise, participants will be able to:

• list the issues facing children with disabilities and their ability to attend school;

• describe at least two practical ways in which they could influence schools, parents or children in order to encourage more children with disabilities to attend school or to have greater access to educational opportunities.

TIMEFRAME

45 minutes

METHOD

Divide participants into pairs. As a short introduction to this exercise, ask the participants to share with each other their experiences of seeing, teaching, helping children with disabilities with their education (N.B. They may have no experience, but that adds to the point of the exercise).

Distribute copies of the **Participants' Notes** for this exercise. Ask the participants to read the case studies and to answer the questions at the end.

Organise a plenary session. Based on the case studies and the participants' own experiences, ask the participants to brainstorm reasons why children with disabilities might be excluded from school. Present and distribute **Handout 5.2: Reasons why Disabled Children Might be Excluded from Primary Education** and show **Overhead 5.2: Factors Influencing the Extent to which a Child with Disabilities is Excluded**.

After discussing these issues in a group situation, ask participants (either in the large group or in their pairs) to reconsider the situation in primary schools in their areas and to think of two ways in which they could influence schools, parents or children in order to encourage more children with disabilities to attend school or to have greater access to educational opportunities.

RESOURCES

Copies of **Participants' Notes** and **Handout 5.2** for each participant.

Copy of **Disability Overhead 5.2**.

Flip chart paper and pen for brainstorm.

Disability

Exercise 5.2: (Participants' Notes)
Why are Children with Disabilities Excluded from Primary School?

OBJECTIVES

By the end of this exercise, you will be able to:

• list the issues facing children with disabilities and their ability to attend school;

• describe at least two practical ways in which you could influence schools, parents or children in order to encourage more children with disabilities to attend school or to have greater access to educational opportunities.

TIMEFRAME

45 minutes

METHOD

You are invited to read the following mini-case descriptions in pairs. They are taken from CBR News, no. 13 1993. Consider answers to the questions that follow:

Mohan

Mohan is a young boy with a mild to moderate disability. He belongs to a wealthy family in a city in South India. His father is well known in the medical profession. Mohan has been provided with everything he needs for his survival and entertainment. He has a suite for himself, a chauffeur driven car and all the electronic media can offer for his entertainment. But he has no friends or occupation and he has not been educated. This means that he has no stimulation that encourages his development.

Lalitha

Lalitha is blind and lives in a village in Andhra Pradesh. Her parents have separated and her grandmother, an agricultural labourer, looks after her. A non-governmental organisation was encouraging disabled people and their parents and guardians to attend their meetings. During one of these, Lalitha's grandmother heard how blind children were going to school and being like other children. She saw photographs that encouraged her to send Lalitha to school even though it is far away.

Ramu

Laxme and Gurumuthy, who have three children, live in a village in Andhra Pradesh. They are agricultural labourers. One day one of their children, Ramu, developed a high fever. Soon his parents realised that he wouldn't be able to walk. Doctors called his illness polio, but Laxmi and Gurumuthy didn't know what that meant. They took him to the quacks, faith healers and witch doctors. They even went to the District Hospital. This meant that one of them couldn't work, leaving them with only one income. They soon got into debt and were unable to pursue their quest to enable Ramu to walk.

From then on, adults and old people in the family and neighbours stopped cherishing Ramu as a child. They stopped carrying him around and playing with him. He grew up as a loner. The other children in the neighbourhood wouldn't accept him and started calling him a "cripple". Ramu had food and clothes but no stimulation. He was seen as a burden and believed that he was useless. Women in the village used to console Laxmi by saying that she and her husband were paying for their sins and sins of their forbears, and that whatever happened to people was in the hands of God.

Ramu need not have been a victim of polio if his parents had known about immunisations. But even if they had access to information, it is presented in a form that would not have been comprehensible to them, and would not have broken through their deep-seated religious prejudices and values. Ramu was not considered to be a contributor because his parents and the villagers had not seen images of children like him looking after children and chickens, picking twigs or going to school, learning a trade and so on.

Questions for discussion:

1. How do the situations of these three children differ?

2. Which child is the "most fortunate"? Why?

3. In your work, have you experienced any similar situations to those described above? Share your experiences with your partner.

Disability

Exercise 6.1: (Facilitator's Notes)
What is Inclusive Education and How Can We Promote It?

TARGET GROUP

Sector Co-ordinators, Field Staff.

OBJECTIVES

By the end of this exercise, participants will be able to:

- explain what is meant by inclusive education;
- describe practical ways of encouraging inclusive education.

TIMEFRAME

45 minutes

METHOD

Brainstorm the question: "What does 'inclusive education' mean to you?"

Using Overhead 6.2, prepare a short presentation about inclusive education using materials from Briefing Notes for Topic 6, and also Reading 6.1.

Divide participants into small groups and hand out the **Participants' Notes**.

Ask the participants to consider the case examples and to share with each other their own experiences/knowledge of situations where children with disabilities have been included in education. The task for the group is to present these positive situations to the whole group as an affirming exercise.

The situations can be presented:

- on a flip chart;
- as a poem/song;
- on a prepared **"talking wall"** (see **ARC Facilitators Toolkit** for explanation);
- any other way the participants can think of!

RESOURCES

Copy of Participants' Notes and Overhead 6.1 for each participant.

Flip chart paper.

Materials for making a **"talking wall"** (if the facilitator chooses to use it).

Disability

Exercise 6.1: (Participants' Notes)
What is Inclusive Education and How Can We Promote It?

OBJECTIVES

By the end of this exercise, you will be able to:

- explain what is meant by inclusive education;

- describe practical ways of encouraging inclusive education.

TIMEFRAME

45 minutes

METHOD

Work in small groups. Read and consider the difference between the two following scenarios:

1.   A severely disabled child in a poor rural community is hidden away in a back room, left alone in her own mess all day whilst her mother works; the father has left after blaming the mother for the birth; the siblings miss school to help with the care of the child and are unable to be married due to superstition. The disabled child has no access to daylight or stimulation and does not receive enough food because the mother does not know how to position her. The mother is isolated within the community and is concerned only with survival.

2.   The same severely disabled child is in a community where awareness has been raised and simple training carried out for rehabilitation volunteers, health workers and school teachers. The child has a corner seat where she sits outside the house every day. Community members come to visit her and the mother belongs to a parents' support group which also does some income generation. School children are encouraged and praised by their teachers when they visit the child and help to teach her basic skills. The rehabilitation worker has developed an educational programme for the child with the mother to prioritise activities of daily living.

The latter situation does not address all the challenges nor solve all the problems, but demonstrates that even a severely disabled child can be included in educational planning – it is not just a matter of location within a school building.

Access to education cannot be separated from issues of quality. The following are examples of a range of ways in which barriers to inclusion in education can be removed:

Lalla in Lesotho has cerebral palsy. The integrated education programme began in Lesotho when Lalla was 12 years old. Initially she started to attend school in a wheelchair and made excellent progress. When the wheelchair broke, her mother borrowed a neighbour's wheelbarrow. When the neighbour wanted the wheelbarrow back, Lalla had to stay at home, but pupils and teachers visit her and have developed a home-based programme for her. The teachers are intending to visit the local health centre to try to persuade the physiotherapist to visit her at home, and to find a way to fix her wheelchair.

Children themselves are often the strongest advocates for educational inclusion:

In Zanzibar, Suleman was 7 years old and was hearing impaired. His younger brother began to attend the local school, but Suleman's mother did not think there would be any purpose in sending a deaf child to school. One day, Suleman stole his brother's school uniform and took himself to school. The head teacher felt that because he had come, he should stay. The teachers use signs with him, he points to pictures, and the children devised an action song, which he can join in. The head teacher believes he has developed a lot of social skills and that his language is improving.

In small groups, consider the case examples and to share with each other your own experiences/knowledge of situations where children with disabilities have been included in education. The task for the group is to present these positive situations to the whole group as an affirming exercise.

The situations can be presented:

- on a flip chart;

- as a poem/song;

- on a prepared **"talking wall"** (see **ARC Facilitators Toolkit** for explanation);

- any other way you can think of!

Disability

Exercise 6.2: (Facilitator's Notes)
Promoting Desirable Change in Society

TARGET GROUP

Sector Co-ordinators, Field Staff.

OBJECTIVE

By the end of this exercise, participants will be able to:

- describe the strengths and weaknesses of different strategies for promoting change within society.

TIMEFRAME

45 – 60 minutes

METHOD

Introduce the topic using the information from the **Participants' Notes** for this exercise. Divide participants into small groups. Distribute copies of the **Participants' Notes** for this exercise and set a time limit for participants to work through the worksheet (30 minutes). Invite brief feedback and questions from each group, before asking them to tackle the second part of the exercise, i.e. to work together in small groups to provide suggestions to answer the following question:

How can desirable change be promoted and facilitated within society?

Plenary: write up suggestions from each group on flip chart.

RESOURCES

Copy of **Participants' Notes** for each participant.

Flipchart paper and pens.

Disability

Exercise 6.2: (Participants' Notes)
Promoting Desirable Change in Society

OBJECTIVE

By the end of this exercise, you will be able to:

- describe the strengths and weaknesses of different strategies for promoting change within society.

TIMEFRAME

45 – 60 minutes

METHOD

Working in small groups, please read the following and discuss the questions. You will have about 30 minutes. There will then be a plenary session where you will be asked to share your answers to question 10.

HOW DOES SOCIETY FUNCTION? WHAT CAUSES SOCIETY TO CHANGE?

What is a society? It is a collection of people who share certain aims, interests and forms of organisation. In all societies people want to be secure from danger and free to live their lives in a comfortable and interesting way. This purpose does not vary although it may be pursued in many different human and environmental circumstances.

The circumstances of a society do CHANGE. This should not surprise us when we remember that all human life is DYNAMIC not static. It is impossible for humans to live their lives in exactly the same way year after year, even if they want to do so. New problems and new opportunities are constantly occurring.

Change is faster in some societies than in others. The rate of change in a society depends on the following factors:

1. KNOWLEDGE and BELIEFS. People are influenced by what they are taught to believe and to think from an early age.

2. ATTITUDES. People are also influenced by the views and opinions that they hear other people around them expressing.

3. PRACTICE. Another way in which people are influenced is through the things they do. They practice many different tasks in their homes, in their occupations and in their relationships with others.

In a particular society people may be encouraged or forced to change for any of the following reasons:

- Their circumstances may change. For example, in an agricultural society the crops may be growing poorer every year because the nutrients in the soil are being used up. The people can no longer gain as much from their harvests as before, so they must either move or find other ways to improve their situation.

- They may be affected by a change in a government policy.

- New knowledge may enable people to do things in a different way, thus improving their quality of lives. For example, when people learn how to sink a borehole or build a dam they can get water more easily.

- People may get a better understanding of a situation, enabling them to make a new approach to it. For example, they may begin to understand that a person with a disability is able to earn an income, contributing to the wealth and comfort of his/her family and community.

_____

How does a society function? Why does it change? How does it change?

We need to think about these questions before we will figure out how we best can help persons with disability to be included in society.

1. When a baby is born, it is helpless. What prevents it from starving to death, being killed by wild beasts, dying of exposure to cold or heat?

2. How does a young child, as it grows, learn to speak, eat food, use a toilet and wash him/her self?

3. How does a growing child learn about his mother, father, sister and brother? How does she/he learn that these people are members of his/her family?

4. Discuss the responsibilities which members of the extended family in your country traditionally have for each other.

5. Do you think it is better for a child to grow up in a rural area surrounded by her/his family or in an urban area with few relatives around?

6. You might have agreed now that children learn about themselves and their families and their village from the way they are treated by the people around them. What will a child with disability learn about him/her self and his/her family if:

   ▪ she is always left sitting in the house and told to keep out of sight?

   ▪ he/she is always fed by others?

   ▪ she/he is never expected to join in tasks around the home?

   ▪ she/he is never included in games or in the play activities of other children?

7. On the other hand, what will a child with disability learn about him/herself if:

   ▪ his/her parents encourage her/him to perform tasks around the house and garden?

   ▪ he/she is encouraged by his parents to join in the play of other children?

   ▪ he/she is always welcome by other children when he wants to play with them?

8. What effects is the behaviour described in question 6 above likely to have on a child with a disability when s/he becomes an adult?

9. What effect is the behaviour described under question 7 likely to have on a child with disability when s/he becomes an adult?

10. Which aspects of change do you consider to be the most important when attempting to persuade people to change their thinking and behaviour.

Disability

Exercise 6.3: (Facilitator's Notes)
Action Planning

TARGET GROUP

Senior Managers, Sector Co-ordinators, Field Staff.

OBJECTIVES

By the end of this exercise, participants will be able to:

- apply their understanding of disability issues within their own working situation;

- devise and explain an action plan for their work in the future.

TIME FRAME

60 minutes

METHOD

Introduce the exercise by presenting **Disability Overhead 6.3**. Divide the participants into pairs and give each person a copy of the **Participants' Notes** for this exercise. Ask participants to work individually in the first instance to complete **Part One** of the exercise: rank the eight principles in the order which they see as most effective *according to their own work situation.* When each person has done this, ask him or her to share their thoughts with their partner. Brief plenary in the whole group (optional).

Now ask participants to complete **Part Two** of this exercise. As with **Part One**, ask the participants to work individually at first and then to share their thoughts with their partner

Hold a Plenary Session.

An optional development to this exercise is for all the participants to write their ideas for **Action for Change** on a group notice board; write a song; make up a poem; devise a slogan: anything that you think might act as an inspiration!

RESOURCES

Disability **Overhead 6.3**.

Copy of **Participants' Notes** for each participant.

Disability

Exercise 6.3: (Participants' Notes)
Action Planning

OBJECTIVES

By the end of this exercise, you will be able to:

- apply your understanding of disability issues within your own working situation;

- devise and explain an action plan for their work in the future.

TIME FRAME

60 minutes

METHOD

In pairs, work through **Part One,** on your own initially, and then share your thoughts with your partner.

Having completed **Part One,** go through the same process with **Part Two,** i.e. working on your own to answer the questions and then sharing your answers with your partner.

PART ONE

The following seven principles, suggested by G.M. Beall in his Social Action Model, will help us to become more effective managers for change. Read the principles and then rank them according to which principle you consider to be most important *according to your own experience and working situation.*

- Recognise and understand the existing social situation

- Define the underlying problem

- Locate relevant groups and institutions which may be used to bring about change

- Communicate with influential people in the area informing them what you are trying to do, and enlist their support

- Diffuse information so that everyone knows exactly what you want to do and why, and also how you intend to do it

- Obtain a commitment to action from involved persons (parents, teachers.)

- Define aims and objectives so that people can see where they are supposed to be going and when they should expect to get there.

PART TWO

Having considered Part One, now think about the following in the context of your work:

Describe one or two strategies for improving the status of children and adolescents in your own working situation that would be realistically achievable by you and/or your working team:

- What steps would be involved in implementing each strategy?

- Who would you need to consult? Collaborate with? How?

- What is the time line for setting up and implementing this strategy?

- What else needs to be considered?

Disability

Handouts

1.1	Children Learn from Their Experience of Adults
1.2	Terms for categories in ICIDH-2
1.3	An Overview of ICFDH-2
2.1	The Situation of Children with Disabilities in Armed Conflict and Displacement
3.1	All Children are Born with Rights - Relevant Articles from the CRC
4.1	Extract from UNHCR Guidelines on "Assisting Disabled Refugees"
5.1	Picture taken from '*Focus on Refugee Children*' by Eva Segerstrom
5.2	Reasons why Disabled Children Might be Excluded from Primary Education
6.1	The Role of Parents' Organisations Within a CBR System

Disability

Handout 1.1

Children Learn from their Experience of Adults

When thinking of *CHILDREN* let us never forget that children learn from their experience of adults.

If children live with *CRITICISM*
They learn to *CONDEMN*

If children live with *HOSTILITY*
They learn to *FIGHT*

If children live with *RIDICULE*
They learn to be *SHY*

If children live with *SHAME*
They learn to feel *GUILTY*

If children live with *TOLERANCE*
They learn to be *PATIENT*

If children live with *ENCOURAGEMENT*
They learn *CONFIDENCE*

If children live with *PRAISE*
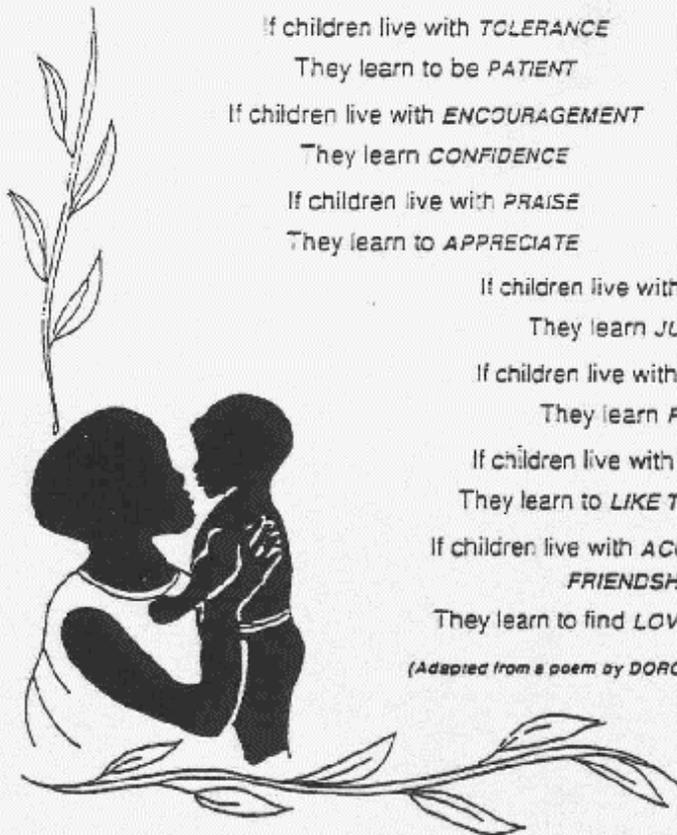They learn to *APPRECIATE*

If children live with *FAIRNESS*
They learn *JUSTICE*

If children live with *SECURITY*
They learn *FAITH*

If children live with *APPROVAL*
They learn to *LIKE THEMSELVES*

If children live with *ACCEPTANCE* and *FRIENDSHIP*
They learn to find *LOVE* in the world.

(Adapted from a poem by DOROTHY LAW NOLTE)

Disability

Handout 1.2

Terms for categories in ICIDH-2

Extract from WHO (2001): International Classification of Functioning, Disability and Health, Final Draft. (Page 157-160).

Well-being is a general term encompassing the total universe of human life domains, including physical, mental and social aspects, that make up what can be called a "good life". Health domains are a subset of domains that make up the total universe of human life.

Health condition is an umbrella term for disease (acute or chronic), disorder, injury or trauma. A health condition may also include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition. Health conditions are coded using ICD-10.

Functioning is an umbrella term for body functions, body structures, activities and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

Body functions are the physiological functions of body systems, including psychological functions. "Body" refers to the human organism as a whole, and thus includes the brain. Hence, mental (or psychological) functions are subsumed under body functions. The standard for these functions is considered to be the statistical norm for humans.

Body structures are the structural or anatomical parts of the body such as organs, limbs and their components classified according to body systems. The standard for these structures considered to be the statistical norm for humans.

Impairment is a loss or abnormality of a body part (i.e. structure) or body function (i.e. physiological function). Physiological functions include mental functions. Abnormality here is used strictly to refer to a significant variation from established statistical norms (i.e. as a deviation from a population mean within measured standard norms) and should be used only in this sense.

Activity is the execution of a task or action by an individual. It represents the individual perspective of functioning.

Activity limitations are difficulties an individual may have in executing activities. An activity limitation may range from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner or to the extent that is expected of people without the health condition.

Participation is a person's involvement in a life situation. It represents the societal perspective of functioning.

Participation restrictions are problems an individual may experience in involvement in life situations. The presence of a participation restriction is determined by comparing an individual's participation to that which is expected of an individual without disability in that culture or society.

Contextual factors are the factors that together constitute the complete context of an individual's life, and in particular the background against which health states are classified in ICIDH-2. There are two components of contextual factors: Environmental Factors and Personal Factors.

Environmental factors constitute a component of ICIDH-2, and refer to all aspects of the external or extrinsic world that form the context of an individual's life and, as such, have an impact on that person's functioning. Environmental factors include the physical world and its features, the human-made physical world, other people in different relationships and roles, attitudes and values, social systems and services, and policies, rules and laws.

Personal factors are contextual factors that relate to the individual such as age, gender, social status, life experiences and so on, which are not currently classified in ICIDH-2 but which users may incorporate in their applications of ICIDH-2.

Facilitators are environmental factors in a person's environment that, through their absence or presence, improve functioning and reduce disability. These include aspects such as a physical environment that is accessible, the availability of relevant assistive technology, positive attitudes of people towards disability, as well as services, systems and policies that aim to increase the involvement of all people with a health condition in all areas of life. Absence of a factor can also be facilitating, for example the absence of stigma or negative attitudes. Facilitators can prevent an impairment or activity limitation from becoming a participation restriction, since the actual performance of an action is enhanced, despite the person's problem with capacity.

Please note: at the time of writing the 2nd edition of the International Classification of Functioning, Disability and Health (ICIDH-2) is in final draft form. This document and further information can be found on the internet from the World Health Organisation at: http://www.who.int/icidh.
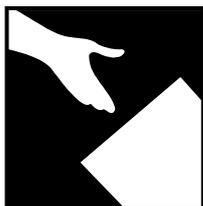
Disability

Handout 1.3
An Overview of ICFDH-2

Extract from WHO (2001): International Classification of Functioning, Disability and Health, Final Draft. (Table 1, Page 9).

	Part 1: Functioning and Disability		Part 2: Contextual Factors	
	Body Functions and Structures	**Activities and Participation**	**Environmental Factors**	**Personal Factors**
Domains	1. Body functions 2. Body structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body function (physiological) Change in body structures (anatomical)	Capacity Executing tasks in a standard environment Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities Participation	Facilitators	not applicable
	Functioning			
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers / hindrances	not applicable
	Disability			

Please note: at the time of writing the 2nd edition of the International Classification of Functioning, Disability and Health (ICIDH-2) is in final draft form. This document and further information can be found on the internet from the World Health Organisation at: http://www.who.int/icidh.

Disability

Handout 2.1
The Situation of Children with Disabilities in Armed Conflict and Displacement

The situation of disabled children in times of conflict needs to be explored further. There needs to be more knowledge about how they, their families and the communities cope with disability in different settings:

A lot of documentation concerning children in armed conflict and displacement deals with so called vulnerable groups. Sometimes this group is defined - but children with disability are seldom mentioned explicitly. As profiles on refugee populations focus on gender and age, boys and girls with disability are generally neglected. There is a danger that this could lead to inadequate interventions or maybe no interventions at all.

This lack of documentation about children with disability in refugee situations leaves many questions unanswered:

- Are there any boys and girls with disability in the refugee camps, did they die or were they left behind?

- Are children with disability not included in programmes directed at vulnerable groups of children in armed conflict and displacement?

- Are these children included in programmes but, for some reason, not mentioned in the documentation?

(Åhlen E. Inventory of Documentation about Children with Disability in Armed Conflict and Displacement, Rädda Barnen 1997)

Disability
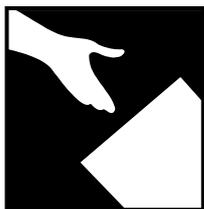
Handout 3.1

All Children are Born with Rights - Relevant Articles from the CRC

Two Articles of the Convention mention children with disability specifically:

Article 2.1: "States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective to the child's or his or her parents..disability..or other status".

Article 23 addresses their special needs: "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".

The rights of the girl/boy with disability are not limited to aspects raised in Article 23 - every article that refers to 'the child' also applies to the child with disabilities. Children with disability should be given the same opportunity to enjoy an adequate standard of living. This includes for example the right to play, the right to survival and development, the right to express opinions in matters affecting him/her, the right to a family, a name and a nationality, but also the right to access education, training, health care, rehabilitation services, and preparation for employment.

Articles 28 and 29: "States parties recognise the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity... and shall be directed to… the development of the child's personality, talents, and mental and physical abilities to their fullest potential…"

The approach of the Convention being holistic, and all the rights being interrelated and indivisible, the Convention constitutes a powerful tool for the protection and guarantee of the rights of children with disabilities.

"The message is about equality of rights. Girls should be given the same opportunities as boys, and children with disability should be given the same possibility to lead a decent life as the rest."

(Hammarberg 'Making reality of the rights of the child' 1990)

Disability

Handout 4.1
Extract from UNHCR Guidelines on "Assisting Disabled Refugees"

TYPES OF INTERVENTIONS:

The possible interventions that can be undertaken in favour of disabled people can be divided broadly into two categories.

GENERAL INTERVENTIONS, INCLUDING THOSE AIMED AT:

- building awareness of disability, of the abilities of disabled people, and of the possibility to provide rehabilitation in the family and the community;

- providing more equitable opportunities, better access to the general systems of society, general interventions in the environment, and so on;

- promoting and protecting disabled people's human rights.

SPECIFIC INTERVENTIONS, INCLUDING:

- functional training in self-care, mobility, behaviour and communication, including provision of appliances and technical equipment to facilitate training and /or to alleviate the consequences of disability;

- also included are environmental interventions in respect of individuals, such as removal of physical barriers for a disabled person, informing and sensitising the family and the community with a view to creating more positive attitudes and less discriminatory behaviour;

- special education calling for resources not available, or not properly used, in regular schools;

- vocational measures, including assessment, formal or informal vocational training, job placement, assistance in setting up small enterprises, etc.
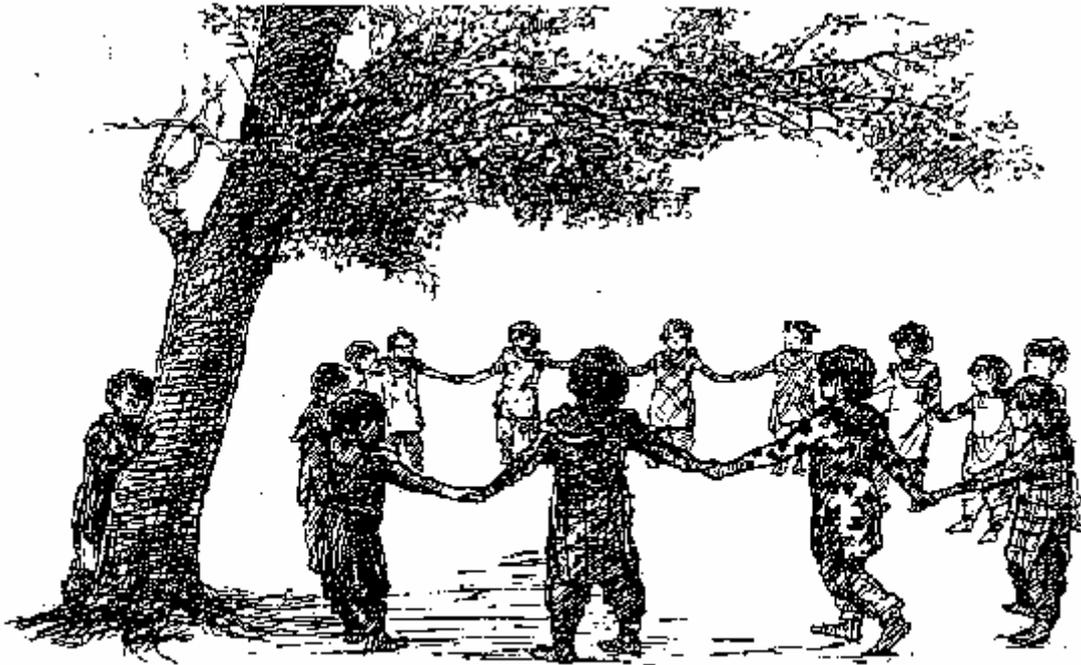
Disability

Handout 5.1

Picture taken from "Focus on Refugee Children" by Eva Segerstrom

Disability

Handout 5.2
Reasons why Disabled Children Might be Excluded from Primary Education

In the experience of Save the Children programmes, disabled children are excluded from local primary schools in many different ways:

One common reason is very simply that parents and the community do not know or believe that disabled children can be educated, that they can learn and develop.

Parents are ashamed of their disabled children and wish to keep them hidden. Even if they are not ashamed, overprotection will often mean that they keep their children indoors and away from school. And if they do not keep their children hidden, often neighbours will criticise them for allowing disabled children to be seen outside the house.

In many primary schools, teachers are poorly trained and the curriculum is often rigid and not very relevant to local communities. In many cases disabled children are left at the back of the class, repeating years, failing and dropping out. Teachers do not have the necessary knowledge and skills and so, even though the children are sitting in the classroom, they are excluded from education.

A simple programme of training and awareness raising for teachers not only enabled those children with impairments to benefit, but also made teaching more child focused and reduced drop-out and repeater rates for all children.

In many rural areas schools can only be reached by long walks; there is no public transport or roads, and mobility-impaired children cannot access them.

Disability

Handout 6.1

The Role of Parents' Organisations Within a CBR System

Extract from "PREJUDICE & DIGNITY" by Einar Helander, UNDP 1994.

Disabled people, their families and their organisations can play an extremely important role within a CBR system.

1. CARE PROVISION

It has already been explained that adult disabled people have a role related to self-care and home-care. In the case of disabled children, it is the family who provides the bulk of home-based rehabilitation. Some disabled persons teach other adults to read and write or contribute to vocational training.

There is evidence that recruiting disabled people as local supervisors for CBR gives excellent results. I am not advocating that all local supervisors should be disabled. Monopoly jobs should be avoided. The same applies to intermediate-level supervisors and specialists at referral levels.

2. SENSITISATION, ANIMATION AND MANAGEMENT OF CBR AT THE COMMUNITY LEVEL

Communities need to be sensitised to the fact that there are many disabled people in their midst and that they have resources at their disposal to handle the major part of the disabled people's service needs.

Disabled people and their families should help in awareness building and stimulate animation locally, help mobilise resources and have an active part in the local management committee.

A particularly useful role can be played by successful disabled adults: in the local schools, for instance. This might be one way of overcoming some of the negative attitudes developed in the past.

As members of the rehabilitation committee, they can become actively engaged in home visits, in analysing the local situation, as well as in proposing vocational training and jobs.

Another area for action is drawing attention to environmental barriers and requesting their removal.

Disabled people should, at this level, also work toward ensuring that they will not be deprived of their human rights. If their human rights are violated, they should approach those in the community responsible for legal protection and ask them to take action.

3. ORGANISATIONS OF PARENTS AND OF ADULT DISABLED PEOPLE

The priority should be to build up local organisations. In our experience, the first one to be set up is often parents' organisation. Later on, disabled adults form their own groups - as a rule they do so at the end of their schooling.

Such groups are to be seen as having social and political functions. It is a place for getting together with others who have similar problems and needs. But an organisation can also act, as an interest group to voice their members' needs vis-à-vis local leaders and authorities. Where there exists more than one such special interest group, joining together in a local federation or in a union, as a more representative body, would give them more political weight.

At a later stage, local groups may join provincial or regional ones and eventually form a national organisation. Again, a union representing all groups of disabled people and their families could be set up and request formal recognition. Such a group would be a valuable partner for the government to consult in all matters concerning services for disabled people. This does not prevent each of the member organisations from keeping its specific profile and from continuing to carry out their social functions. A national federation or union can play a significant political role, making the public aware of the problems disabled people face and of the contributions they can make to society. Many such unions have approached political parties and other powerful groups to promote their ideas.

As pointed out with reference to the community level, disabled people's organisations have a crucial role to play when it comes to promoting environmental changes and seeking protection of their human rights. The authorities must be made aware of the fact that providing services and opportunities is not enough.

Regrettably, in most developing countries the development of organisations seems to start more often than not from the top and not from the grass roots. It is also unfortunate that there should be such fragmentation and lack of cohesion, considering the adverse effects this has on the attention of the government will give to these interest groups. The goal should be to obtain formal recognition of the union or federation as a government partner, and to formulate and apply formal procedures for consultation.

No single international organisation is yet fully representative of all the interests related to disabled people. Maybe this will not be possible - or necessary - in the future. There is little coincidence of interests between such diverse group as parents concerned about the future of their disabled children, elderly people worrying about their dependency in daily life activities, wheel chair users confronted with the problem of access to transport and public buildings, blind people without adequate supply of information or of deaf people seeking to develop their own culture, and so on. With interests being so diverse and social, cultural and economic conditions varying widely, each group may want to stay independent. This notwithstanding, disabled people can play an important role in international development - as expressed by Tambo Camara in his introduction to a recently published book: "Disabled people in the developing world, instead of taking a wait-and-see attitude and remaining passive, are getting organised to change public attitudes on the one hand and to demonstrate the role they can play in the development of their countries on the other." An example of a political

expression from an international organisation of disabled people is reproduced in Box 13.1.

Disabled people should not confine themselves to joining their own separate associations. Rather, they should strive to become members of groups of non-disabled people representing political, cultural, religious, social, environmental and other interest. Integrating themselves in this way will serve to sensitise all such groups to the special needs of disabled people.

4. ASSISTANCE TO ORGANISATIONS OF DISABLED PEOPLE AND OF PARENTS

In order to carry out their political and organisational roles, may organisations in the developing countries need economic assistance.

This is often provided by sister organisations in the industrialised countries, or through donor development agencies. One of the most often-cited needs is assistance in administrative and leadership training. There are examples of both special courses, held exclusively for disabled people or parents' groups, and general courses bringing together disabled people and members of other types of Egos such as women's organisations, environmental groups, scouts and community development groups.

Transport is another major area where assistance is required. There are frequent request for cars, buses and tickets for transport by air. No doubt it is costly to set up regional- or district-level organisations and to arrange meetings of their respective representatives. Few of the existing organisations can meet such costs.

More co-operation is called for in efforts to strengthen the role of these organisations.
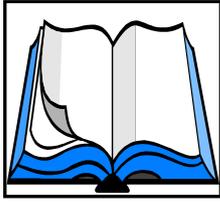
Disability

Readings
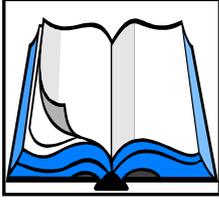
Disability

Reading 1.1

Some of the More Prevalent Illnesses and Conditions Which Result in Disability

The following descriptions of the forms of disability that are likely to be most prevalent in developing countries are taken from David Warner's "Disabled Village Children", published by Hesparan Foundation, ISBN 0 942 364 06 6.

POLIO:

In many countries polio is still the most common cause of physical disability in children. In some areas, at least one of every 100 children may have some paralysis (muscle weakness) from polio. Where vaccination programmes are effective, polio has been greatly reduced.

Polio is caused by virus and the infection attacks part of the spinal cord - where it damages the nerves. In areas with poor hygiene and lack of latrines, the polio infections spread when the stool of a sick child reaches the mouth of a healthy child. Where sanitation is better, polio spreads mostly through coughing and sneezing.

Only a small percentage of children become paralysed when infected by polio. Most only get what looks like a bad cold.

Is the paralysis contagious?

NO, not after 2 weeks from when a child first gets sick with polio. In fact most polio is spread through the stool of non-paralysed children who "have only a cold" caused by the poliovirus.

Once a child is paralysed what changes or improvements can be expected?

Often the paralysis will go away, partly or completely. Any paralysis left after 7 months is usually permanent. The paralysis will not get worse.

What are the child's chances of leading a productive happy life?

Usually very good, provided the child is encouraged to do things for him/herself, for example to play with siblings, to go to school and learn things. Intelligence is not affected by polio.

Can persons with polio marry and have normal children?

Yes, polio is not inherited and does not affect the ability to have children.

CEREBRAL PALSY

Cerebral Palsy means, "brain paralysis". It is a disability that affects mostly movements and body position. It comes from brain damage that happened before the baby was born, at birth, or as a baby. The whole brain is not damaged, only

parts of it, mainly the parts that control movements. Once damaged, the parts of the brain do not recover, or get worse. However the movements, body positions and related problems can be improved or made worse depending on how we treat the child and how damaged his or her brain is. The earlier we start the better.

Causes:

Before birth:

- *Infections of the mother while pregnant, i.e. German measles.*

- *Difference between the blood of the mother and the child (Rh incompatibility).*

- *Mother has diabetes or toxaemia during pregnancy.*

- *Inherited - is very rare.*

- *No causes can be found in 30% of the children.*

Around birth: for example

- *Lack of oxygen.*

- *Birth injuries.*

- *Pre-maturity - babies that are born early.*

After birth: for example

- *High fever due to infection or water loss from diarrhoea.*

- *Brain infections (meningitis).*

- *There are many causes including malaria and tuberculosis.*

Cerebral Palsy is not contagious - it cannot be passed from one child to another.

Can people with cerebral palsy marry and have children?

Yes, and the children will not have Cerebral palsy (except in very rare types of cerebral palsy).

Will my child ever be able to walk?

This is often the biggest concern of parents. Walking is important both functionally and socially, but in terms of the child's needs, other skills may be more important. For the child to lead as happy, and an independent life as possible, necessary skills and accomplishments are:

- *Having confidence in yourself and liking yourself.*

- *Communication and relationships with others.*

- *Self care activities such as eating, dressing and toileting.*

- *Getting from place to place.*

We all need to realise that walking is not the most important skill a child needs - and it is certainly not the first. Many severely affected children may never walk. We need to accept this and aim for other important goals. Whether or not the child may someday walk, he/she should participate in activities that other children do and then he/she needs other skills i.e. ways to get from place to place.

SPINA BIFIDA

Spina Bifida is a defect that comes from a problem in the very early development of the unborn child. It happens when some of the backbones do not close over the centre tube of nerves. As a result a soft unprotected area is left, which may bulge through the skin as a dark bag. The future of a child with spina bifida depends on how serious the defect is, the medical care and on the family and community support.

A child with a defect that is low down on the back usually has less paralysis and has a good chance of living a full and happy life.

SPINAL CORD INJURY

This results from an accident that breaks or severely damages the central nerve cord in the neck or in the back, i.e. falls from trees or mules, car accidents, diving accidents, bullet wounds. How much of the body is affected depends on the level of the injury along the backbone. The higher the injury is the greater the area of the body that is affected.

When the spinal cord is damaged so completely that no nerve messages get through, the injury is said to be complete. Feeling and controlled movement below the level of the injury are permanently lost. If the injury is "incomplete" some feeling and movement may remain, or feeling and controlled movement may return little by little during several months. In incomplete injuries, one side may have less feeling and movement than the other.

Will my child be able to walk?

This will depend on how high or low in the back the injury is. The lower the injury, the better the chance of walking. A person with complete spinal cord injury in the neck has no chance of walking. She will need a wheelchair.

However, it is best not to place too much importance on learning to walk. Many children who do learn to walk find it so slow and tiring that they prefer using a wheelchair.

Let the child decide what is the easiest way for him/her to move about.

LEPROSY

Leprosy is an infectious disease that develops very slowly. It is caused by germs (bacilli) that affect mostly the skin and nerves. It can cause a variety of skin problems, loss of feeling, and paralysis of the hands and feet.

Leprosy can only spread from people who have untreated leprosy, and only to other people who have low resistance to disease. It is probably spread either through sneezing or coughing, or through skin contact.

Leprosy can be cured by medicine that kills the germs. However the treatment in some people must be continued for years to prevent the disease from coming back. Early treatment is important because it stops the spread of leprosy to others, also if treatment starts before loss of feeling, paralysis, and deformities have appeared, recovery is usually complete and the person is not physically or socially disabled.

FITS (EPILEPSY)

Fits are sudden usually brief, periods of unconsciousness or changes in mental state, often with strange jerking movements. One out of every 10 to 20 children has at least one fit by the age of 15. But only one in 50 of these children go on to have chronic fits - a condition known as epilepsy.

Fits come from damage to, or an abnormal condition of the brain.

Common causes include:

Injury to the brain. Injuries may be before birth, during birth or at any time after. The same causes of brain damage that result in cerebral palsy can cause epilepsy. In fact, cerebral palsy and epilepsy often occur together.

Meningitis is a common cause of this combination. In small children common causes of fits are high fever or severe dehydration.

Hereditary. There is a family history of fits in about 1/3 of persons with fits.

Unknown causes. In about 1/3 of people who have epilepsy there is no family history or no history of brain damage can be found.

What to do when a child has a fit

Learn to recognise any "warning signs" that a fit is about to begin, such as sudden fear or cry. Quickly protect the child by lying her down on a soft mat or other place where she cannot hurt herself.

When a big fit starts, do not try to move the child unless she is in a dangerous place.

Protect the child as best you can against injury, but do not forcefully try to control her movements. Remove any sharp or hard object near her.

Do not put anything in the child's mouth while she is having a fit - no food, drink medicine, nor any object to prevent biting the tongue.

Between spasms, gently turn the child's head to one side so that saliva drains out of her mouth and she does not breath it into her lungs.

After the fit is over, the child may be very sleepy and confused. Let her sleep.

BLINDNESS AND DIFFICULTY IN SEEING

Difficulty in seeing can be mild, moderate, or severe. When a person sees very little or nothing we say he/she is blind. Some children are completely blind, they cannot see anything. However most children can see a little. Some can only see the difference between the light and dark of day and night, but cannot see any shapes of things. Others can see shapes of large objects, but none of the details.

Some children with cerebral palsy or other disabilities are also partly or completely blind. Parents may not realise this and think the child is slow in his/her development. In fact blindness can be the large part of the cause. Even if a child has no other disability, blindness can make development of early skills slower and more difficult. If the child does not look at, reach for, or take interest in things around him/her, check if she/he can see and hear.

Common causes:

"Dry eyes" especially common in parts of Africa and Asia. It results when a child does not get enough Vitamin A (naturally in fruits, vegetables, milk, and meats). Dry eyes develop in children who are not regularly fed and it often appears or quickly gets worse when the child gets diarrhoea or has measles, whooping cough or tuberculosis. It is much more common in children who are not breast-fed.

Trachoma is the most common cause of preventable blindness in the world. It often begins in children and may last for months or years. If not treated early, it can cause blindness. It is spread by touch or flies and is most common in poor and crowded living conditions. It can be prevented by keeping the eyes clean and keeping flies away.

River blindness is a very common cause in parts of Africa and Latin America. It is spread by a kind of black fly that breeds in rivers and streams.

Measles, which can injure the surface of the eyes. Especially common in Africa and in children who are poorly nourished.

Brain damage causes blindness in many children, usually in combination with other disabilities, i.e. cerebral palsy.

DEAFNESS

A few children are completely deaf. Parents often notice that their child cannot hear, because the child does not turn her head or respond even to loud sounds. Some children who are partly deaf hear a little when people speak to them. They may slowly learn to recognise and respond to some words, but many words they do not hear clearly enough to understand. They are slow to begin to speak. Often they do not speak clearly, mix certain sounds, or seem to "talk through their nose".

Unfortunately sometimes parents, other children and teachers do not realise that the child has difficulty in hearing. They may treat the child as if he/she is mentally slow or "dumb". This only increases the child's problem. For a child with hearing loss the biggest problem is learning to communicate, because he/she cannot hear the words clearly it is much more difficult to learn to speak.

Common causes before the child is born:

Hereditary - in certain families although the parents may not be deaf. Usually the child has no other disability and learns quickly.

Measles during early pregnancy.

Common causes after birth:

Ear infections especially long lasting repeated ear infections with pus present.

Meningitis.

MENTAL RETARDATION

Mental retardation is a delay or slowness in a child's mental development. The child learns things more slowly than other children his/her age. The child may for example be late at beginning to move, smile, show interest in things, or the child may develop some of these skills more quickly but be slower in others.

Mental retardation ranges from mild too severe. The child who is mildly retarded takes longer to learn certain skills, but with help he/she can grow up to care for him/herself and take an active part in the community. The child who is severely retarded, as he/she grows older may stay at the mental age of a baby or young child.

Mental retardation cannot be cured, however all children with mental retardation can learn, contribute and develop as other children, but maybe in a "different" way.

Causes:

Often the cause is not known.

Some children are born with a very small brain.

Sometimes there is a mistake in the chromosomes - this is what happens in Downs Syndrome.

Sometimes the mother did not get enough of a certain food or mineral during pregnancy.

Brain damage can happen either before, during or after birth.

Measles or Meningitis.

WHO has estimated that 70% of the disabilities in developing counties are caused by such preventable factors as malnutrition, communicable diseases, inadequate pre-and post-natal care, and accidents. Children often suffer multiple disabling impairment, for example physical injuries and psychosocial trauma. The breakdown of services that occurs in emergency can cause disabilities or make them worse. Injuries, burns, severe eye and ear infections and psychosocial trauma are common in emergencies and can cause disabilities. In armed conflict, for every child killed, an average of three others sustain disabling injuries.

The public health and primary health care measures fundamental to emergency response are Key elements to prevent any types of disabilities. Likewise measures that increase the physical safety of children help prevent disabling conditions. Rapid assessment, outreach and screening are needed early in an emergency to identify vulnerable children and families, including those at risk due to disabilities.

Prevention

Primary prevention measures block the incidence of disabling conditions. Ensuring all children have access to basic health care is fundamental to preventing disabilities. Secondary prevention measures involve the early identification and treatment of health problems (malnutrition, ear and eye infections, serious injuries) to reverse their effects and prevent them from becoming worse.

In the initial stage of an emergency, give priority attention to measures such as:

Measles vaccination; Oral Rehydration Therapy; Vit. A prophylaxis; supplementary feeding for the most seriously malnourished children; contingency planning to control any outbreak of disease that may threaten the public health. The nutritional status of children 6 - 39 months is particularly vulnerable. Often in emergencies where food rations are provided these consist largely of whole grains that infants and young children cannot easily digest. It is essential that provision is made for grinding and, if necessary, special rations so mothers can prepare suitable foods.

Disability
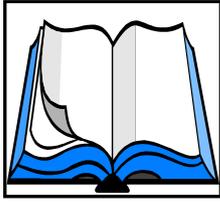
Reading 2.1
"Violence and the Disabled Child"
by Naomi Richman (McKeith Press, 1995)

The needs of disabled children are basically the same as those of other children, but in situations of violence and conflict it becomes more difficult to ensure that these needs are met, and that adequate protection is provided for more vulnerable children.

There is very little written about disabled children in conflict situations, but we would expect conflict to increase the numbers of physically impaired children, and to make life more difficult for those with existing conditions. Their problems are exacerbated because most conflicts occur in developing countries, where children are already at a higher risk of impairment due to poverty and limited health care, and where resources for disability services usually do not have priority.

The disabling *psychological* effects of conflict have received more interest than the physical effects, and we can only speculate about the interaction between psychological and physical factors in these situations.

EFFECTS OF VIOLENCE AND CONFLICT

The increasing impact of modern conflict on the civilian population has been noted by many authors (e.g. Zwi and Ugalde 1989). It is common for up to 80 per cent of casualties to be civilian, with the majority being women and children. This holds true whatever the type of organised violence: "conventional" combat, repressive regimes, civil war, wars of liberation and insurgency, or so-called "low intensity" warfare. Terrorising the population has become an important weapon in many conflicts, and chemical warfare, defoliants and bombs reach civilians either deliberately or coincidentally. In particular the various types of modern land mine, often laid without any regard for civilians, are an increasing long-term menace (Human Rights Watch Arms Project 1993).

Even after direct conflict is over, poverty, destruction of the economy and of the infrastructure, and other constraints such as sanctions, continue to affect the health of large sections of the population (Lee and Haines 1991). It is the poorest who are most affected by war and its aftermath (Zwi and Ugalde 1991), as is also the case in disasters such as earthquakes (Cuny 1983).

Prolonged situations of violence often lead to gradual "militarization" of society, with freely circulating arms and a social acceptance of violence. Coupled with social and economic disruption, this is a potent brew in which criminal violence flourishes, often linked with drug dealing. Family tension, alcoholism and domestic violence also grow when there is poverty and social instability.

In the post-war period, returning soldiers face a difficult readjustment to family life, especially if they are disabled and unemployed. Young people frequently form a high proportion of the armed forces: they encounter special problems in readjustment because they have had few chances to learn about the social skills for civilian survival. Their situation is especially precarious when they have no family.

In all these situations children with impairments are more vulnerable as they need extra care and time, and so are an added strain on the family. However, even in the most desperate situations parents do find ways of giving this care.

CONFLICT AND DISABILITY

Conflict affects the occurrence of impairment in a number of ways. First, we have seen that children's well-being is affected by poverty and social disruption. Second, basic health services are disrupted directly, and resources for preventive and curative health care are reduced, because they are directed toward oppression or conflict (Zwi and Ugalde 1991). The activities of existing maternal and child health programmes, such as immunisation, are disrupted or even disappear completely (Dodge 1990, Cliff and Noormanhomed 1993). Malnutrition increases, and specific nutritional deficiencies (e.g. iodine, vitamins) are not addressed.

Children thus become more susceptible to a variety of infections such as measles, poliomyelitis and diarrhoeal diseases, and are less able to resist their effects. An increased incidence of conditions such as motor impairment, hearing and visual problems following measles, and cerebral damage due to malaria, ensure. Intellectual impairment is increased because of lack of stimulation and deprivation, and because of direct insults to the brain, including nutritional deficiencies, infections and injury.

Disabled children are also less likely to escape during an attack, especially if they have a motor or learning difficulty or for other reasons are unable to look after themselves. A girl affected by poliomyelitis in Mozambique described to me how she had to be carried away by others whenever her village was attacked. Although she praised the concern of her relatives and neighbours, she became increasingly anxious about her situation and was eventually placed in an educational boarding school far from her family.

Special efforts may be made to protect such children, but sometimes this is impossible because only the toughest survive the hardships of flight. Parents have to make agonising decisions as they fee, about how many children, and which children, they can manage to protect. Children, too, are consumed with guilt about siblings they had to abandon during flight.

The number of disabled people found in refugee camps will depend on the age of the camp, and the standard of living available. It is unusual to meet disabled people in newly arrived populations, presumably because they did not survive, but as time goes on, and provided that nutrition and care are reasonable, the numbers will probably rise.

INCIDENCE AND PREVALENCE

Although the *incidence* of impairment increases in war, affected children are less likely to survive due to inadequate health care, so that the overall *prevalence* probably falls.

It is difficult to investigate the prevalence of impairment during times of war. Most conflicts occur in developing countries and we would expect to see similar patterns to those found in peace time plus war injuries. The type of conflict obviously affects the nature of injuries incurred. These vary from the effects of aerial attacks, chemical weapons and conventional warfare, through to those of "low intensity" warfare, which might include deliberate mutilation of children.

The most common problems found in a survey of children in two provinces of Cambodia in 1986 affected hearing and speech, motor performance and learning capacity. The most frequent cause of motor impairment was poliomyelitis, followed by land-mine injuries and other accidents, and cerebral palsy. The overall rate of disability in children aged 0-15 years was estimated to be 2.57 per cent (Ministry of Health, State of Cambodia 1992).

War wounds, including those resulting from land-mines, produce large numbers of physical injuries including amputations, as well as conditions like blindness, deafness due to perforated eardrums, head injuries and facial disfigurement. Mines continue to cause injury long after the end of conflict. They can remain active for more than 70 years and pose a long-term threat both to individuals and to economic recovery in countries such as Cambodia, Afghanistan, Angola and Mozambique. Because mines remain lethal for long periods and because by their nature they are indiscriminate in their targets, it is now argued that under the UN convention on weapons their use should be banned (Human Rights Watch Arms Project 1994).

A study in Cambodia by King (personal communication, 1992) suggested that children were less likely than adults to be involved in land-mine accidents. However, this is surprising since children are more likely to run around over a wide area, tending animals or going into the bush to collect firewood. When a child steps on a mine and is wounded, the injuries are likely to be fatal or at least more severe, because of the child's size. The long time taken for civilians to reach medical care and the lack of adequate acute services add to the death toll.

PSYCHOLOGICAL CONSEQUENCES OF CONFLICT

Investigation of the psychological consequences related to conflict is more complex than for physical impairment, because it requires careful and culturally relevant interview techniques. Studies of adults suggest that following conflict, rates of psychological problems are higher than those of physical ones (Summerfield and Toser 1991).

There is little adequate information about the psychological consequences in children. Recent studies have looked especially for evidence of post-traumatic stress disorder (PTSD) related to specific "traumatic" events such as witnessing the murder of a relative (American Psychiatric Association 1987). Symptoms of the disorder include intrusive images of the "traumatic" events in the forms of dreams or sudden vivid memories (flashbacks), avoidance of reminders of the events, and somatic symptoms.

The emphasis on symptoms of PTSD as the *sole* indicator of the disabling effects of conflict has been questioned for a number of reasons (Richman 1993a). Although surveys have described severe psychological effects following exposure to conflict, these studies have based their findings on brief questionnaires about symptoms. However, mere symptom counts based on questionnaire data cannot indicate the degree of *functional* impairment, and it is difficult to know the effect this has on their everyday lives.

In addition, focusing on PTSD ignores both the importance of chronic stress such as lack of food and recurrent threat on children's psychological state, and also the results of loss and bereavement as major influences on their adjustment.

A group of 60 children in Mozambique who were displaced inside the country because of fighting were interviewed about their views of the conflict and their emotional state (Richman *et al.* 1989). They described anxiety and fear, often precipitated by possible threat such as groups of men in the distance or sudden loud noises; difficulties in sleeping and nightmares; sadness related to loss and violence; and somatic symptoms such as fatigue, headache and stomach ache, limb pains, or unpleasant bodily sensations. Approximately a quarter were markedly affected by their symptoms. The majority were living in very bad conditions, suffering from separation from family, continuous threat and deprivation. None of these children were physically impaired, although many suffered from malnutrition and chronic ill-health due to bilharzial or other infections.

When estimating the extent of psychological impairment it is important to know how long symptoms persist, but this may be difficult to do in war situations, and most studies have relied on cross-sectional data. In another study of 60 Mozambican children, one year after the initial contact (Draisma and Richman 1992), threat of attack had diminished and the

general situation was calmer. In those re-contacted there was a considerable reduction in somatic symptoms and anxiety, overall mood had improved, and they were generally more optimistic. One of the group was now dependent on crutches following an attack of poliomyelitis. However, it was only possible to contact about half of the original children, as many had returned to their home villages.

The severity of emotional distress experienced by children in situations of war and disaster depends on a variety of factors. These include the degree of threat; the intensity of the exposure to violence, especially towards family or self; the extent of bereavement and loss; and whether protective adults are available. Young children are particularly distressed if they have become separated from all familiar adults (Raphael 1986).

Most children appear to recover their equilibrium over a period of months if they are in a reasonable environment with a caring family, and are not subject to the threat of attack. Unfortunately many children continue to live in harsh and threatening circumstances and this prolongs their distress.

UNACCOMPANIED CHILDREN

Death of relatives or separation from family are probably the most serious consequences of conflict for children. Children with no family (orphaned, separated or abandoned) are especially vulnerable. Their intellectual and emotional development is likely to be affected if they have no adult(s) consistently to provide emotional and physical care, when they will also be at risk of emotional and sexual abuse. Abuse can occur in any kind of social situation, but children in institutions or in foster family where there in inadequate supervision are particularly at risk. Disabled children are more often picked out as victims because they may be less able to defend themselves.

Prevention of separation should be a priority, and any steps that separate a child from the family even if this is supposed to be temporary, require careful consideration (Ressler 1992). There is often pressure from outside the country to evacuate children to safety of for medical reasons. Sometimes this benefits the children, but often the results are unfortunate and the relationship between the child and the family is seriously affected. The child and family may remain apart for long periods, perhaps forever; or the conditions of care for the evacuated may turn out to be poor and the children suffer misery and feel abandoned. Children evacuated for medical treatment, either within their own country or abroad, may then be unable to rejoin the family, because transport home is impossible, the war zone changes, or because the whereabouts of the family is unknown. It is common for such children to languish in hospital for months, or even years, like a boy in Mozambique who had already been in hospital for over a year following an amputation after a land-mine injury (Human Rights Watch Arms Project 1994).

It can be a difficult ethical issue to decide whether evacuation for medical treatment will be in the best interests of a child with impairment. If it is decided to send children away for treatment they should be accompanied by a relative or at least an adult whom they know. The details of the child and family should be thoroughly documented so that there will be a good chance of reuniting them should communication be broken for a time. This may seem obvious but can easily be forgotten in acute situations in hospital emergency departments, for example. When children are evacuated there must be adequate supervision at the point of arrival and afterwards because there is a risk that they will be exploited for example, used as prostitutes or servants.

Ideally, unaccompanied children should be placed in foster families or small group homes while attempts are made to locate relatives. Such a programme of family tracing was initiated in Mozambique during the recent war, combined with a policy of not building extra orphanages for these children. There were only one or two small orphanages per province, and many children were spontaneously fostered. However, adoption or fostering

of children with impairments is difficult, especially in times of social unrest and if there is no assistance for the extra costs incurred. There is a risk that some children will be taken in by families with the aim of exploiting them: for example, for begging purposes, or to obtain extra food.

Orphanages tend to have a concentration of disabled children because the children are more likely to be left there by parents wanting to give them a better chance of survival. Once accepted they are unlikely to leave because the family will not reclaim them.

Usually orphanages provide a poor environment for children especially when they are young or have special needs. Staff have had no training in understanding the needs of children with impairments and are poorly paid. The lack of individualised attention to the children and of permanent affectionate ties impairs their emotional and intellectual development (Aberg 1991). When the time comes eventually to leave the institution they have no family or community in which to integrate.

Due to the disadvantages of orphanages and the difficulties of arranging adequate alternative care, it is of the utmost importance to prevent separation, and where it has happened, to try to find the family. The possibility and difficulties of tracing relatives should be carefully explained to the child, and the mechanisms set in motion as soon as possible (Williamson and Moser 1987). It must be borne in mind, of course, that some families are unwilling to receive their children.

PSYCHOLOGICAL EFFECTS OF DISABILITY

Various factors influence the psychological state of disabled children - the type of impairment; how and when the impairment was acquired; the attitude of the community; family resources and the resilience and resourcefulness of the child.

Type of impairment

Western studies indicate that any kind of chronic illness increases emotional difficulties. The causes are multifactorial and include the effects of hospitalisations and unpleasant treatments, upset about limitations on normal activities, anxieties about future well-being and life chances, and parental responses. These last may vary from extreme over-protectiveness to ignoring or denying the child's needs.

It appears that organic brain conditions increase vulnerability in children already at risk because of difficult social situations. Children with epilepsy and organic brain disorder, for example following head injury or infection, or with severe learning difficulties, have the highest rates of psychological impairment (Rutter *et al. 1970).* Problems with hearing, speech and communication are also associated with high rates of psychological difficulties.

In developing countries it is common for parents to hide away children with severe physical impairment or severe learning difficulties, who then have no opportunity to develop their capacities. However, we have little information about how they are affected emotionally by this situation. When the family does not accept an impairment, as when parents continually look for a healer with an effective cure for epilepsy or slow learning, this places further strain on a child.

How and when the impairment was acquired

The shock of receiving an injury may be long lasting. One boy aged 5 years was present when his house was attacked and his father was killed before his eyes. He himself suffered a deliberately inflicted gunshot wound to his right arm, which had to be amputated. On leaving hospital he went to live with his uncle in a safer place. Initially he was terrified of men, especially those in uniform, did not play and would not use his left arm; he had been right-handed. Over a period of more than a year he lost his fear of

unknown men, began to attend school, made friends and studies, and was cheerfully using his left hand. However, he still had difficulties falling asleep, and his impairment was a constant reminder of the attack and the loss of his father.

Community attitude

Chapters 11 and 12 have discussed the powerful effects of community attitudes to disabled children on their adjustment. In some situations the war wounded hold a special place in society, as for example Palestinian youth honoured in the fight for national independence, and youth in various political struggles who have been detained and tortured. Permanent injury inflicted because of brave resistance will earn a child great esteem, as happened to a boy in Mozambique who had the finger of one hand and both ears cut off because he refused to disclose his father's whereabouts. However, such honouring can gradually fade, and the pride of disabled children in their sacrifice also fades if the long-term prospects of work and marriage are minimal, or the results of sacrifice do not bear political fruit.

The side on which a person fought often determines their future, depending on which group ends up with power and the degree of national reconciliation. Even those who became disabled in defending their country may find that they are marginalized once peace comes, and resources to help them are scare (Zinkin 1993). Others, who were involved in committing atrocities, might be ostracised and forced into a marginal existence or even criminal activities.

When nearly everyone is living through hard times, and when the war wounded are a common sight, community support for an individual child may lessen, from both adults and other children. Even when the impairment has obviously been acquired in war, if the ultimate causal explanation of their injury is seen as sin, fate or witchcraft, there may be lack of will to help.

The family

Whatever the particular causal explanations understood by a family, their capacity to accommodate a child with an impairment will depend a great deal on their resources, both personal and material. Those in the process of resettlement, or dealing with instability and poverty, will have less capacity to help. During conflict more fathers are away fighting or working, or perhaps dead, and more households are headed by women who have to earn a livelihood as well as bring up children. Economic difficulties, exacerbated by war, make it harder for families to look after their disabled children; the provision of resources and means of livelihood for such families helps to create a more positive attitude and lessens the risk of the child being abandoned.

The child

We have described how an impairment adds to a child's vulnerability in dangerous situations. However, children vary in their responses and their capacities to cope with danger and their impairment. They often show great courage in facing hardship, and it is no service to pity them rather than promote their independence. One boy who had a damaged leg following a bullet wound had worked out very carefully how he would escape should an attack materialise. A girl who used crutches to get around looked after three younger brothers and sisters and went to school, as well as doing odd jobs for money.

Factors that are related to children's resilience in the face of adversity include having a range of coping strategies which they can use flexibly. When action is impossible they can resort to useful mental mechanisms to help them cope with their situation, such as day-dreaming, fantasy, distraction, blocking out unpleasant thoughts, or mentally rehearsing possible responses to the situation.

Coping capacity is to some extent learnt through adult example and personal experience, and children can be helped to improve their skills through discussion of their anxieties and of coping strategies.

PROMOTING COPING SKILLS

Disabled children affected by conflict need similar support to that required by other children, especially the possibility of confiding in an understanding adult.

Information and participation

Adults are often reluctant to speak with children about their situation or their impairment. This is excused by saying that the child is too young to understand. The child is left with anxieties unexpressed, or lacking essential information, for example about the feelings associated with a phantom limb, or the degree of improvement expected after poliomyelitis.

In busy clinics, especially in conflict situations, no one has responsibility for explaining the condition and possible future help to the child or the family. Indeed, health workers may not be able to speak the child's language, or be familiar with the culture, so that opportunities for essential explanations and follow-up are lost. This communication is particularly important for conditions like epilepsy, where often ideas about causation militate against adequate treatment.

Trained health advocates, who need not be health worker, could convey these important explanations, and provide information to relatives about how they can help a child with an impairment.

Wherever possible, children should be involved in making decisions themselves, for example, about fitting a prosthesis, or about where they are going to live.

Working with the family

In situations of war or in refugee camps it is not easy to initiate programmes of support for disabled children, but it is important to do as much as possible, otherwise valuable time is lost, during which the child should be learning and developing. Discussions with local communities may bring up useful ideas about what would be feasible.

Most families are very pleased to have the possibility of help providing it is relevant to their needs: for example, a day centre so that mothers can work; physiotherapy advice; and practical aids, exercises or occupation for a child. At the very least, discussions could aim at encouraging adults to communicate with children about their situation, and ensure their integration and participation in the wider community, particularly if schooling is available.

A variety of initiatives have been described for supporting women affected by conflict, especially those with children. These include involving mothers in group discussions or activities such as setting up and running pre-school centres (Fozzard and Tembo 1993). In this way the morale of the mothers is raised and they are more able to respond to the needs of their children.

Promoting integration

Whenever possible, disabled children should be involved in normal activities with other children. 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 disabled children, and ensure they are not marginalized, and that their capacities and special 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 disabled children (Child-to-Child 1993).

Responding to the child's emotional distress

In some cultures it is not customary for people to talk about how they feel; they appreciate concern expressed through practical help that provides prospects for the future. However, some children have emotional problems related to their impairment, their family and the sufferings of war and separation. They need the opportunity to express their feelings and anxieties to an understanding adult who is open to whatever they want to say (Richman 1993b).

Sometimes group discussions are helpful, when participants can see that they have common concerns, and can talk about practical matters related to coping with discrimination or violence, or ways of contributing to the family or community when physical work in the fields is not possible.

Children with persistent distress related to experience of war need special attention, as well as care for their material needs. Even in situations of continuing conflict it has been possible to develop programmes of response to children's psychological needs. Common elements are the provision of as normal a routine of life as possible, especially schooling; recreational and creative activities like sports, games, art and drama; opportunities to talk and express their feelings; and working with parents (Gustafsson 1986; Ministry of Education, Mozambique 1990).

These kinds of programmes are relevant to the needs of all children whether they have impairments or not. Their value can be extended if linked with the training of teachers, health workers or volunteers in simple counselling skills to support children and families (Metraux 1988, Nikapota and Samarasinghe 1989, Richman *et al.* 1991, Jareg 1992, Metraux and Aviles 1992). Training should include raising awareness about disability and disabled children (Richman 1993b)

CONCLUSION

The situation of disabled children in times of conflict needs to be explored further. We need to know more about how they, their families and communities cope with disability in different settings. We also need to explore what kinds of help have been developed locally for disabled children caught up in conflict, and what initiatives it might be useful to try out in the future.

Although conflict situations make if difficult to provide for disabled children, there are a variety of actions that can promote their well-being. These include:

- reducing the number of unaccompanied children by avoiding separation from family, careful documentation of those who are separated so that relatives can be located, and establishing a programme for tracing families and reunification;

- sensitising parents, the community, teachers and others about the needs of all children for supportive adults who are prepared to listen to their concerns;

- integrating children with impairments into ordinary life as far as possible;

- developing schools, leisure and creative activities from which all children can benefit;

- international advocacy to ban the use of land mines completely - an urgent priority.

Disability
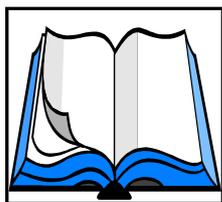
Reading 4.1
A Description of Community-Based Rehabilitation

A DESCRIPTION OF COMMUNITY-BASED REHABILITATION

by Dr.Einar Helander, UNDP, Geneva, 1993

Community-based rehabilitation (CBR) is a strategy for improving service delivery, for providing more equitable opportunities and for promoting and protecting the human rights of disabled people.

It calls for the full and co-ordinated involvement of all levels of society: community, intermediate and national. It seeks the integration of the interventions of all relevant sectors - educational, health, legislative, social and vocational - and aims at the full representation and empowerment of disabled people. It also aims at promoting such interventions in the general systems of society, as well as adaptations of the environment that will facilitate their social integration and their self-actualisation. Its goal is to bring about a change; to develop a system capable of reaching all disabled people in need and to educate and involve governments and the public, using in each country a level of resources that is realistic and maintainable.

At the community level, CBR is seen as a component of an integrated community development programme. It should be based on decisions taken by its members; and it will rely as much as possible on the mobilisation of local resources. The family of the disabled person is the most important resource. Its skills and knowledge should be promoted by adequate training and supervision, using a technology closely related to local experience. The community should support the basic necessities of life and help the families who carry out rehabilitation at home. It should further open up all local opportunities for education, functional and vocational training, jobs etc. The community needs to protect its disabled members to ensure that they are not deprived of their human rights. Disabled community members and their families should be involved in all discussions and decisions regarding services and opportunities proved for them. The community will need to select one or more of its members to undergo training in order to implement the programme. A community structure (committee) should be set up to provide the local management.

At the intermediate level, a network of professional support services should be provided by the government. Its personnel should be involved in the training and technical supervision of community personnel, should provide services and managerial support, and should liaise with referral services.

Referral services are needed to receive those disabled people who need more specialised interventions than the community can provide. The CBR system should seek to draw on the resources available both in the governmental and non-governmental sectors.

At the nation level, CBR seeks the involvement of the government in the leading managerial role: planning, implementing, co-ordination, and evaluating the CBR system in co-operation with the communities, the intermediate level and the non-governmental sector, including organisations of disabled people.

Comment: When applying the CBR strategy one needs to be flexible. It is a learning process, not a blueprint or a ready-made solution. One must take into consideration the current social, cultural and economic situation, the situation of the disabled people, the country's existing services and personnel, phase of development, and so on, as well as the country's own priorities and policies. Projects or programmes that do not apply the basic principles of CBR, on the other hand, should use another term to describe their activities.

COMPARING URBAN AND RURAL CBR

Following is an extract taken from CBR News no.19, 1995, where Shaya Asindua (formerly working for AMREF in Eastern Kenya compares an urban CBR programme with a rural CBR Programme and asks whether they represent different models.

I would like to share my experience of working in urban and rural CBR programmes in Kenya. I will draw comparisons from the two programmes I have worked in; one in Nairobi, Kenya's capital city, and one in Kibwezi, a rural area.

Before we look at the differences, it is important to examine what the two CBR programmes have in common with each other.

Both programmes work with poor, low-income families.

Both programmes have the same basic aims; to make disabled people more self-reliant and independent.

Both programmes started through the efforts of non-governmental organisations (NGOs) and then received government support.

Despite these similarities, the two programmes provide different learning experiences. Their histories and settings create different advantages and constraints in providing a CBE service.

NAIROBI - AN URBAN PROGRAMME

The Nairobi Family Support Services (NFSS) programme covers three large areas of Nairobi, called Kibera, Kangemi and Dagoreti, where housing conditions are poor. Most residents have migrated to Nairobi from rural areas in search of work or in the hope of a better life in the capital.

The CBR programme began in 1981 and grew out of a grandfather's wish to provide schooling for his grandson who had cerebral palsy. The grandfather tried to enrol his grandson in a special school for severely handicapped children in Loresho (a rich area of Nairobi). However he could not afford to pay the fees and transport costs. He then decided to invite the headmaster to a meeting in Kibera

with other disabled children and their carers. The meeting developed into a playgroup, which was the beginning of the CBR programme. The link with the school was maintained through joint staff training and exchange programmes.

NFSS was one of the first CBR programmes in Kenya and has been used by both NGOs and the government as a model for other programmes. Today the project has six paid staff and works with over 200 disabled children, most of whom have some form of mental handicap.

NFSS is managed by a local committee of parents, community leaders, disabled people from the Nairobi area, and CBR professionals, including programme staff. The project's activities include playgroups, home visits, training, and production of appropriate equipment. Young adults receive training in home care and vocational skills.

KIBWEZI - A RURAL PROGRAMME

The Kibwezi CBR programme is based in Madueni District in Eastern province. 200 kilometres from Nairobi. It is a semi-arid area with a population of 170,000 mainly from the Akamba ethnic group.

Like NFSS, this programme also started modestly. In 1982 ActionAid Kenya trained its field workers to identify disabled children and refer them for appropriate action, whether medical or schooling. At the same time AMREF (African Medical and Research Foundation) was running a community-based primary health care programme. In 1987 the two agencies made a joint proposal for a comprehensive CBR programme for Kibwezi in collaboration with the Kenyan government.

In 1988, together they carried out a survey of disabled people in the district. They found six per cent of the population under the age of 15 years had some disability, with the main causes being malnutrition and birth trauma. Families with disabled children tended to hide them away or not to talk about them. To overcome their isolation, parents were encouraged to bring children to playgroups and to share their own feelings and experiences in parent support groups. Today the Kibwezi programme works with over 1,600 disabled children and adults, covering many disabilities.

The Kibwezi programme emphasises community involvement, including the use of local skills and appropriate technology in community centres, schools and workshop. A new development is the Kibwezi Disabled People's Organisation, which actively involves disabled people.

Disability
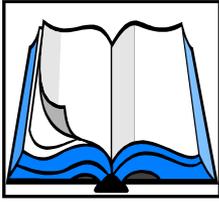
Reading 6.1

From "Schools for All" by P. Khatleli, L. Mariga, L. Phachaka & S. Stubbs

INTRODUCTION TO THE LESOTHO PROGRAMME

The integrated education programme in Lesotho is a national programme which aims to include all primary schools. It is being implemented by the Ministry of Education with support from international Non-Government Organisations, such as Save the Children (U.K.) and the United Nations agencies.

The programme is innovative in a number of ways. One central aspect is the focus in changing teachers' attitudes, knowledge and teaching methodology in order to enable a broader range of children to benefit within a mainstream environment. There will be no separate cadre of teachers, no separate training courses, certificates or salaries, and no special units. Existing special schools (only four) will be used to support integration in the mainstream primary schools. Parental education and involvement is seen as crucial, together with a range of other sectors of society such as organisations of disabled people, different professionals and different government ministries. Children with all types of disability, over a wide age range are being supported in the programme; many are already in schools, and others have been integrated as a result of the programme.

LESOTHO: THE COUNTRY

Lesotho is a small mountainous kingdom surrounded by the Republic of South Africa. Harsh winters and high altitudes make much of the country inaccessible in winter. The population is estimated at 2 million, mostly consisting of Basotho peoples whose language is Sesotho. For over a hundred years, until independence in 1966, Lesotho was a British Protectorate. Throughout its history, Lesotho's economy and stability has been inextricably linked to that of South Africa where a quarter of the workforce has sought employment (Mariga and Phachaka 1993a). Lesotho is divided into 10 districts, with Maseru as its capital.

The provision of education in Lesotho is a joint venture between the Government, churches and the community. In 1992, there were over 370,000 children in primary schools, which is about 75% enrolment (Lesotho Ministry of Education 1992). The pupil-teacher ratio is estimated at 54:1, and about 85% of teachers are qualified. However, a study conducted in 1990 shows a high drop-out rate; nearly 80,000 children are enrolled in grade 1, with less than 30,000 remaining in grade 7, and two thirds of these are girls.

TRADITIONS BELIEFS AND PRACTICES

The birth of a Disabled Child: The traditional beliefs and practices surrounding disability are a complex mixture stemming from practical experience, the need for survival, spiritual beliefs and traditional attitudes to health. When a disabled child is born, this is usually perceived as negative. The mother in particular feels responsible, and is desperate to discover the cause. Some beliefs about causes include contact with other disabled people when pregnant, witchcraft, incest, evil spirits, lack of proper attention to ancestral spirits

and heredity. Health professionals often contribute to this negative response by breaking news in an insensitive manner or concealing information.

Coping Strategies: Once the child is born, there are several possible consequences. The marriage may be threatened, although strictly speaking there can be no divorce because a Basotho woman does not marry her husband; she marries into the family or lineage and so is the wife of that lineage. The woman will feel responsible for the child and will believe it her duty to keep the child at home in order to please the spirits. Greater misfortune could befall the family if the child was sent away and came to any harm. Boy children are more desired than girls are, and for disabled boys, greater effort will be made to seek a "cure".

A variety of coping strategies exist within traditional Basotho culture. The extended family system of care depends on a complex system of responsibilities and reciprocations, which ensure that the needs of family members are met despite the destabilising influences of migrant labour and cash economy. These are supported and perpetuated by Basotho customary law and indigenous education (Simms, undated). An indigenous system of parent education is still practised and helps parents better understand their disabled child, the causes of the disability and coping strategies needed. This occurs informally for members of extended families and formally for adolescents at initiation schools. The extended family also contributes towards the non-formal education of the disabled child, focusing on self-care and activities of daily living. Social integration within the community is regarded as very commendable amongst the Basotho, and children are encouraged to play with, and to help disabled children.

Education and Employment: Although education is usually not prioritised for the disabled child because there are no perceivable benefits, many disabled children do attend school. The feasibility study revealed that 17% of primary school children experience a learning difficulty related to visual and hearing impairment, mental handicap and other disabilities (Mariga and Phachaka 1993a).

Most begin school at a much older age than their peers. There could be a range of reasons for this including parents waiting until they have gained basic social and functional skills, a lack of knowledge about the benefits of schooling, and delayed access to mobility aids. However, primary schools in Lesotho already accommodate a very wide age range, particularly for boys who often spend many years herding animals and then begin or re-join primary school in their late teens. Although these disabled children are physically and socially integrated and teachers often try to help them, the relevant knowledge and skills to meet their specific education needs is missing (Snell 1987).

Employment is also assumed not to be an option because children with disabilities are discriminated against or the workplace is not accessible. Not surprisingly, disabled children and adults often lack self-esteem and face may other difficulties in developing their full human potential.

ORIGINS OF THE PROGRAMME

Prior to the 1980s, specialist provision for disabled children had been the responsibility of NGOs, churches and individuals. During the Decade of Disabled People (1983 - 1992), disabled people, parents and their organisations began to demand national educational provision for disabled children. At the same time the concepts and language of universal human rights, social justice, solidarity and individual dignity were spreading and gaining support and influence. Lesotho, in the heart of South Africa, was inevitably strongly affected by this. It was increasingly recognised that marginalised and vulnerable groups need to participate in change and to become empowered to promote their own development. Education is one key to this empowerment.

In 1987, the Lesotho Ministry of Education funded by USAID, commissioned a consultant, Marg Casapo from Canada, to undertake a study and devise guidelines on special education. This work initiated the process of policy development and programme planning which led to the current programme. The report by Casapo (1987) highlighted that the small number of institutions offering specialist care and education no only violated the traditional care-taking practices of the Basotho extended family, but they were costly, were unable to meet more than a minority of needs, and were even detrimental to the child's emotional and psychological wellbeing. She made several recommendations including:

- build on traditional care-taking practises.

- promote integration into mainstream schools.

- use specialist services in a more targeted way and ensure they support mainstream education.

- promote sustainability by making programmes self-supporting.

- up-grade teacher training.

- provide itinerant special education teams to support mainstream teachers.

- encourage families to send their children to school.

- promote public information on disability.

- include special education in both in-service and pre-service curricula.

From 1988 to 1990, discussions developed between the Ministry of Education, the Lesotho National Federation of Disabled People and Save the Children Fund (UK). SCF is an international non-governmental organisation. SCF was developing its disability work within the Southern African region, and became instrumental in finalising the Special Education policy and developing an operations plan for its implementation.

The Ministry of Education sent the Head of the Early Childhood Education Department. Lineo Phachaka to the United States to study special education in order to be able to implement the programme on her return. The 1990 conference on Education for All (Jomtien) also gave added impetus to promoting the integration of disabled children.

In 1991, the Special Education Unit was founded within the Ministry of Education. SCF seconded Lilian Mariga, a special educationalist with extensive practical experience from Zimbabwe, to work in collaboration with Lineo Phachaka to develop and implement the programme.

FEASIBILITY STUDY

In line with the principles of participation and the importance of respecting and building on traditional beliefs and practices, an extensive feasibility study was carried out. The aim of this study was:

to provide baseline information which will enable the Ministry of Education to

implement its stated policy of promoting the integration of children with special

educational needs into the regular school system at all levels. (Mariga and Phachaka 1993)

The specific objectives were: to create awareness about the policy among primary school teachers; to assess the numbers and types of children with special needs already in primary schools; to investigate the attitudes of teachers, pupils and parents towards integration, and to identify pilot schools. A sample of 314 randomly selected primary schools (26% of all schools) in 8 of the 10 districts formed the basis of the study in which

2,649 teachers, a sample of pupils in grades 5, 6 and 7 and nearly 1,000 parents were interviewed.

The study took over six months and was very thorough; providing not only a wealth of information on which to build an appropriate programme but also involving the community right from the initial stages of implementation. Some of the key results included;

- Over 17% of all primary children had some sort of impairment which affected their education; including visual, hearing, physical and learning impairments; mental retardation and epilepsy among others.

- Children with learning disabilities formed the largest group (over 12% of children in school).

- Over 85% of teachers were in favour of the policy of integration.

- All the pupils interviewed were in favour of integration as were 99% of parents. A small number of parents feared their children would be ridiculed, or that disabilities may be contagious.

- Physical conditions of schools were very poor for all children and were mostly inaccessible to wheelchair users.

- Although teachers do their best to help slow learners, they lack the knowledge, skills and support to benefit them significantly. The teachers welcomed the idea of further training.

Whilst the feasibility study indicated that integration was feasible, it also highlighted some constraints to implementation. The existing policy did not have guidelines on implementation and there was no documentation on the existing specialist services. The largely NGO-funded specialist centres (twelve schools with 400 children) had negative attitudes towards integration and many of their policies and practises contradicted the government policy. There was a lack of both human and material resources; only one trained education officer, and no books or equipment.

Their constraints were overcome in a variety of ways. There was no intention to close down the special schools. A long process of awareness raising and discussion helped staff realise that they had a role to play in support of the process of integration.

The Special Education Unit formulated its own objectives for implementation. These included: the development of curriculum materials and training in their use; piloting the material and integrating children in ten pilot schools; the development of a parent-training manual, on-going awareness-raising at all levels, and finally, the integration of the curriculum into the National Teacher Training Pre- and In-service training curricula. Substantial time was taken after these objectives were formulated to discuss them with key people in the Ministries of Education, Social Welfare and Health, and with Disabled People's Organisations and special school staff.

KEY PRINCIPLES

The principles at the heart of the programme are a blend of the best of traditional Basotho approaches to education and disabled children, and of the thinking on disability and education in relation to human rights which has been developing globally, particularly over the last decade (Helander 1993). These three principles can be summarised as follows.

1. **Human Right and Social Justice**

- Equality: disabled children are children first and should have equal rights, opportunities and dignity.

- Social Integration: disabled children belong with their families and communities.

- Social justice: services and opportunity should be available to the community as a whole and not limited to small privileged groups.

- Solidarity: responsibility for fostering human life is shared by all. Society has a duty to offer support to those who need it.

2. Involving communities

- Participation is a basic human need and essential for ensuring sustainable and appropriate change.

- Indigenous beliefs and practices should be respected and built on in innovatory programmes.

- Commitment and involvement at all levels is necessary for successful integration (i.e. policy-making, administrative, training, school, community and family levels).

3. Schools and society must change to include all children

- Impairment is a feature of the individual, but disability is caused by the barriers - attitudinal, organisational, environmental - which society builds to exclude children and adults with impairments.

- All children can learn and have a right to education within their communities.

- Difficulty in learning is a normal part of schooling: children are all individuals.

- All children benefit from flexible and child-centred approaches to teaching.

- Mainstream schools have a responsibility to cater for pupil diversity.

- Learning should be meaningful and relevant to the context and cultures.

- Promoting inclusive education requires that attitudes and power structures change; barriers to inclusive education need to be removed and negative stereotypes and discrimination should be challenged.

- Education is the responsibility of the whole community, and collaboration between parents/carers and teachers is central.

INTEGRATED OR INCLUSIVE EDUCATION?

The term "integration" is used to refer to a wide range or practices that have very different impacts on children. If the child is seen as "the problem", then integration will focus on trying to make the disabled child fit into the existing system. Children will be described as "not being able" to be integrated into existing mainstream classrooms, and therefore exclusion or separate provision (including special units) are justified. With this individual model, there will be an emphasis on professional diagnosis of the child and on identifying their "problems" but very little emphasis on changing professional attitudes and the environment. In this approach, the impression is that disabled children are separate or special groups, yet in reality there is no clear dividing line between children.

Another approach, which also comes under the heading integration, is based on very different principles;

- all children have a range of different abilities.

- all children can learn.

- all children can experience difficulty in learning.

In this model, if certain individuals are excluded then the focus will be on identifying those barriers which exclude them. In education, these include policies (or lack of policies),

teacher methodology, curriculum, attitudes, lack of knowledge and skills, school buildings and general development issues such as poverty and lack of transport.

This approach does not deny the fact that a disabled child is "different" but says that being different is not a negative thing. In fact it can be positive. The disabled child is encouraged to be proud of who she is and positive disabled adult role models are seen to be an inspiration to all children. This approach which focuses on the responsibility of the teacher and adaptation of the environment also means that other marginalized groups benefit, such as linguistic or ethnic minorities or traumatised children. The aim is to include *all* children, not just to integrate a chosen few. For this reason "*inclusive education*" is increasingly being used as a more accurate term for this fundamentally different approach.

This latter approach forms the basis of what is meant by integration in the Lesotho programme. Change is a process however, and the environment and attitudes cannot be changed overnight. Schools aim to reach large numbers and to achieve certain basic goals. This has to be balanced with individual needs. Furthermore, education is not only the responsibility of schools, and sometimes the home/community environment supported by a CBR programme is a more effective way of providing appropriate education for the small minority of severely disabled children. Although the term "inclusive education" has been developed from policy and practice in the West, in many ways this is a much more accurate way of describing the traditional approach to education in Basotho society. Schools do not exclude children provided they can get there and their parents are able to send them. Also the traditional non-formal education systems ensure that all children benefit from some sort of education.

IMPLEMENTATION STRATEGIES

The implementation of the inclusive education policy was based on the twin themes of awareness raising and on the development of indigenously produced curriculum materials.

Awareness-raising: Awareness-raising activities were considered to be integral to the whole process of implementation. During the feasibility study itself, awareness of the policy on integration was raised amongst the community and most professionals. Later, specific workshops were run for the Special Education Curriculum Committee, District Education Officers, school managers, local chiefs, district administrators and parents of children with and without disabilities.

Training workshops on special education were held for the ten pilot schools (see later) together with the seven district resource teachers.

A 45 minute recording was produced on special education to be broadcast to the public on radio Lesotho.

Finally, a meeting was held with the National Teacher Training College director and staff to prepare them for the inclusion of the curriculum component into the mainstream syllabus. A key issue here is that the policy of including disabled children in schools was not presented as an option or a luxury, but as a government policy which needed to be implemented.

In addition to written reports, the whole programme has been recorded in a series of informal video programmes. These are not only an excellent means of documenting the programmes' progress but also provide an accessible and effective resource for awareness raising.

Curriculum Materials: The feasibility study had revealed that there was hardly any literature on special education existing within Lesotho. Teachers needed access to basic information about impairment and teaching methodology, which they would be able to

refer to during, and after, training. Therefore the development of curriculum materials was one of the first tasks.

In line with the principles of participation and consumer representation a *Special Education Curriculum Committee* was formed in order to develop and review the materials. The committee had the following representatives from the following institutions: Ministries of Education, Health and Social Welfare, the University of Lesotho, National Teacher Training College, Lesotho National Federation of the Disabled (LNFOD), Early Childhood Development Department, International Labour Organisation (ILO), parents of children with and without disability, two physiotherapists, and teachers from mainstream and special schools.

The first draft of the materials consisted of curricula for in-service teacher training, syllabi in different areas of disability, an assessment booklet, along with in-service and pre-service training course content. The committee met regularly to review these materials paragraph by paragraph.

In addition to the primary aim of producing appropriate and relevant materials, this painstaking process meant that the committee not only gained considerable knowledge about impairment and teaching methodology, but professional barriers were broken down as the subject of special education was "de-mystified" and made accessible and understandable to the wider community.

These materials were produced in order to be incorporated into the mainstream curriculum. Whenever and wherever possible, the child would follow the existing curriculum but given the limitations and relative inflexibility of this curriculum, it was recognised that some children needed individual programmes.

PILOT SCHOOLS

The ten pilot schools identified during the feasibility study were chosen in order to reflect a range of situations. A balance of schools, which had positive, negative and neutral attitudes to integration were chosen. Schools in close proximity to special schools and those in remote areas were included. The ten schools are from eight of the ten districts in Lesotho. The pilot schools each had about twenty children identified as disabled in some way. They had a range of different impairments and covered a wide age range.

Training of Personnel: Once the draft materials were produced, they were presented to the heads of programmes at the Ministry of Education. A one-day workshop was organised for twenty-four District Education Officers to introduce them to the materials. A similar workshop was run for managers of schools. The participants were very positive about the materials and pledged their support to teachers.

From the pilot schools, one teacher from each grade, plus the headteacher, attended a three week, in-service training workshop on the materials. They received 120 hours of training in this initial workshop. The resource persons were all from within Lesotho and included both professionals and disabled people from LNFOD. At the end of the workshop some of the headteachers and class teachers who had felt negative about integration were some of the most enthusiastic and committed advocates.

Although teachers had initially attended with some reluctance - giving up some of their holiday - the main feedback from teachers at the end was that the training had made teaching in general more interesting and had improved their overall teaching skills and understanding of how children learn.

Follow-up workshops were then held at six monthly intervals in which teachers' recommendations and request from the previous workshops were incorporated. For example, there had been a strong request for many of the key lectures to be repeated at the first follow-up. All the schools wrote and submitted their own reports on their piloting of

integration. These hand-written reports are included in the official workshop report and provide colourful insights into the very practical experience of integration;

Integration does wonderful things; "Mathabo came to school without speech, but she now speaks! She came from home with her mouth open, but now she can close her mouth, even when she is not reminded." (Mount Royal School).

"We have come across some problems, but our feeling is that the programme will succeed since there are teachers who support the programme, and luckily they are hard workers. Above all the community we are serving is very pleased and would like to see the programme live." (St.Bernadette's Primary School).

(Mariga and Phachala, 1993b).

Each of the pilot schools is involved in raising awareness with their neighbouring primary schools as well as running their own workshops and training courses for parents and other teachers.

Parents: All disabled children are different, and so are their families and their response to their disabled child. Recognition of the distinctive and unique characteristics of each family in central to the programme, and the approach to partnership with parents is flexible.

The involvement of the parents at all stages is a key principle of the programme. However it was also realised that in order to promote the sustainability of the programme, parents should take responsibility and not expect everything to be provided by professionals and government ministries.

Therefore in response to the needs of a parent of a child with severe learning difficulties the Special Education Unit encouraged the formation of a Parents' Association, which has been twinned with a Norwegian Association of Parents of Children with Mental Handicap (NFPU), who provided the funding for this endeavour.

The Parents' Association then invited Mrs Mariga and Mrs Phachaka to run workshops for them on mental retardation and behaviour modification. It was a real eye-opener to parents that they had a role to play in modifying the behaviour of their children if they were to succeed in an integrated programme. A parent training manual has been developed and workshops given to parents involved in pilot schools. Parent workshops include parents of non-disabled children who often have concerns about how the programme will affect the education of their children. There are plans to establish a resource centre, which will be controlled and run by parents.

Assessment and Programming: There is a plethora or Western-developed tests which are inappropriate and invalid in the context of Lesotho. The Unit decided that assessment tools needed to be developed and standardised in the social and cultural context in which they would be used. Other considerations were that materials should be local and easily accessible, and that the tests should be simple and usable by local teachers and parents. Examples include covering one eye with a mug when using the "E" chart, and using a mug and spoon as a rattle to test hearing.

Following the feasibility study, the Special Education Unit identified an Education Assessment Team (EAT) whose task is to support the teachers in developing their own assessment skills. The EAT consists of an orthopaedic technician, teachers of children with intellectual impairments, teachers of hearing and visually impaired children as well as the members of the Special Education Unit. The team visit the pilot schools and assesses children, giving advice to parents and teacher, makes referrals (e.g. for eye and hearing tests) and works with parents, teachers and other professionals to draw up Individualised Education Programmes (IEPs). They run workshops for teachers on the use of the assessment booklet and to support the training they have already received.

The focus is very much on responding appropriately to the child's learning needs rather than on labelling.

Networking: From the start, it was recognised that the disabled child and their family are part of a community and have a range of different needs and priorities, not just educational. It was also realised that meeting the educational needs of disabled children would involve all levels of society, from government to community, and would require collaboration and involvement of different sectors such as heath and social welfare.

The networking started with policy makers and other key people in different departments in Ministries of Health, Education, Social Welfare, Teacher Associations, Disabled Peoples' Organisations, and key institutions such as the University, Teacher Training College, National Curriculum Centre, teachers from the Resource Centre, Community-Based Rehabilitation (CBR) personnel and Parents' Associations.

Regular consultation meetings are held with policy makers and teacher trainers, and they are represented on the Curriculum Committee. The Lesotho Federation of Disabled People (LNFOD) has been committed to this programme since its initiation, and is represented on committees as well as being involved in the planning, training and placement of students. Staff from the Special Education Unit have also participated in the LNFOD Disabled Activist Training workshops. There are currently three CBR programmes operating in Lesotho. Liaison includes awareness raising, assessment, parent training, referrals and school placements.

Special school staff have been involved throughout and are encouraged to offer a supportive role but there have been problems in this area. Almost all the existing Special Education Centres are non-governmental and provide long term care facilities which are expensive and disruptive to family life. They lack clear objectives and insufficient staff to give a sound education. Attempts to involve staff at the planning stage met with a lot of resistance. This is partly because they feared their schools would be closed down. However, the recommendation from Casapo's report stated clearly that they should have a role as resource centres (Casapo 1987) so there has been a continuing effort to assure the special school personnel that they do have an important role, albeit a different one. Disabled children in special schools are now encouraged to spend some time in local mainstream schools.

SUSTAINABILITY

Finally we consider some of the issues which affect the sustainability of this integration programme.

Structures: Throughout the piloting stage, meetings have been held with the National Teacher Training College and it is envisaged that the Special Education Component will be included in the professional studies programme by 1996. The ten pilot schools will be used for teacher placements. Knowledge about different impairments and about teaching methodology, which responds to pupil diversity, will then be institutionalised and fully integrated within the Lesotho teacher training systems. There will be no special course, certificates or special salaries; the content and methods will be an aspect of good teaching practise for all children. The specialist teachers will be part of the normal district resource team which is an itinerant team which supports schools on a range of issues.

Resources: Resources have been limited throughout. A lot of care was taken to ensure that the programme was not over-resourced at an unsustainable level. Over-resourcing also can create competition and power struggles and makes true participation very difficult. The Special Education Unit consisted of only two officers (Mrs Mariga and Mrs Phachaka) for the first two and a half years of the programme. All materials had to be created by the Unit; this ensured that they were kept simple and were locally available. Financial and technical support has been provided by donors such as SCF and UNICEF

but in such a way as to promote the development of internal financial and technical support.

Government Commitment: The Ministry of Education has now budgeted for the training and curriculum development aspects of the programme. They have also provided additional staff. Throughout the programme, efforts have been made to establish a wide funding base. UNICEF funded the initial feasibility study, Save the Children Fund channelled the funds from Comic Relief to pay the salary of the Special Education Advisor along with various other contributions, and the Norwegian Parents' Association funds the Lesotho Parents' Association.

Participation: The most important contribution towards appropriate sustainability has been the careful attention paid to the participatory process. This has often meant that different aspects of the programme have taken much longer than if the Special Unit has just "got on with it". The Special Education Unit officers Mrs Mariga and Mrs Phachaka prioritised this process by going out to many different groups of people, spending a lot of time with them, listening to them and learning from them. The aim was to ensure that the whole programme was firmly rooted in the positive aspects of existing belief and practice. As in a traditional Basotho partnership, the knowledge and skills developed in other countries has been married into the Lesotho lineage of traditional family care and now that the whole community has been involved, there can be no divorce!

IMPACT

The programme has gained national recognition from policy makers, parents and many professionals. Attitudes have begun to change, in some cases in quite radical ways. Teachers have developed confidence, knowledge and skills which help them become better teachers of all children. A major strength is the establishment of formal and informal networks and support systems involving different sectors and levels of the community.

There have of course been constraints. Progress may have been faster with more resources but then again, the steady development has meant that the roots are firmly established. The programme has had to respond to external influences such as political instability within Lesotho, and also the major upheavals in the region due to the dramatic changes in South Africa.

Internal constraints such as changes of staff and the pressure for other aspects of educational reform have also had to be worked with. The changes that teachers are being asked to make are fundamentally different from traditional ways of working and teachers are not used to being agents of change. The approach used involves all levels in order to offer maximum opportunity for support and success; the government policy and national plan provides a very important basis for change, the involvement of several teachers plus the headteacher from the pilot schools ensures a whole school approach and mutual support, and the networking and community involvement ensure that the changes are relevant, appropriate and integrated into indigenous belief and practice.

THE FUTURE

The long-term goal is that the programme will become an integral component of mainstream education. It may also be a model for other countries in the region to learn from, as it offers an alternative approach to other integration programmes operating in Africa. The issues of early childhood education and vocational training and employment are very closely related to the programme. It is hoped that increased collaboration with CBR and LNFOD, together with continued inter-ministerial collaboration will ensure that the goals of "equalisation of opportunities and full participation" are getting closer. A full evaluation of the programme is planned for May 1995, eighteen months after the piloting of training materials.

Disability
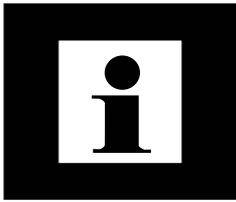
Further Readings and Websites

RECOMMENDED READING

World Health Organisation, Second Edition of the International Classification of Impairments, Disabilities and Handicaps (ICIDH-2). WHO, Geneva.

UNHCR, Community Services Guidelines on Assisting Disabled Refugees: A Community-based Approach (1996). UNHCR, Geneva.

Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1994). United Nations, New York.

Salamanca Statement and Framework for Action on Special Needs Education, UNESCO 1994.

FURTHER READING

Zinkin, McConachie, Mittler (1995): Disabled Children and Developing Countries. McKeith Press.

Abu-Habib, L. (1997): Gender and Disability – Women's Experiences in the Middle East. OXFAM, UK.

Hastie, R. (1997): Disabled Children in A Society At War. OXFAM, UK.

Coleridge, Peter (1993): Disability, Liberation and Development. OXFAM, UK.

Save the Children Sweden (2000): Focus on Refugee Children, A Handbook for Training Field Refugee Workers in Social and Community Work. Save the Children Sweden, Stockholm.

Åhlen, E. (1997): Inventory Of Documentation About Children With Disability In Armed Conflict And Displacement. Rädda Barnen, Stockholm.

Berglund, A. (1997): A Matter of Social Context – The Sexual Abuse of Children with Disabilities, Rädda Barnen, Stockholm.

Save the Children Alliance, Promoting Psychosocial Well Being Among Children Affected By Armed Conflict And Displacement, 1996

Hammarberg T (1996): Making Reality of the Rights of the Child. Rädda Barnen, Stockholm.

Helander, E., Prejudice and Dignity, UNDP, ISBN 92-1-126032-9 (out of print).

WEB-SITES

World Health Organisation (WHO)
http://www.who.int/icidh/

The homepage of the International Classification of Impairments, Disabilities and Handicaps. ICIDH-2 can be viewed at this site.

http://www.who.int/chd/

WHO's Child Health and Development (CHD) website.

International Labour Organisation (ILO)
http://www.ilo.org/public/english/employment/skills/targets/disability/index.htm

Homepage of the ILO's "Disability and Work".

UNESCO
http://www.unesco.org/education/educprog/sne/index.html

General information on special needs education including the text of the Salamanca Statement.

OXFAM
http://www.oxfam.org.uk/publish/socdiv.htm

This address links you directly to OXFAM publications and can be used for ordering the three publications listed in the further reading section.

Save the Children Sweden
http://www.childrightsbookshop.org/

This is the homepage of Save the Children Sweden's child rights bookshop and can be used for ordering their publications.