UN Convention on the Rights of Persons with Disabilities

Preamble:
Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child.

Article 3, General Principles:
Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 4, General Obligations:
In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Article 7, Children with Disabilities:
1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.
OBJECTIVES

The background information and exercises contained in this chapter will enable participants to work towards the following objectives:

- Understand discrimination against children with disabilities as a human rights issue
- Understand the interrelation and interdependence of the rights of children with disabilities and other human rights
- Identify ways in which the rights of children with disabilities have been promoted or denied
- Explain the importance of allowing children with disabilities a voice regarding issues that involve them
- Understand and apply the provisions on the human rights of children with disabilities in the UN Convention on the Rights of Persons with Disabilities (CRPD)
- Highlight possible strategies to advance the rights of children with disabilities.

GETTING STARTED: THINKING ABOUT THE HUMAN RIGHTS OF CHILDREN WITH DISABILITIES

Children as a whole are marginalized; however, some groups of children, such as children with disabilities, girl children, and children from ethnic minorities face even greater discrimination. Children with disabilities are uniquely at greater risk for discrimination due to the fact that 1) they have a disability and 2) they are children and therefore more vulnerable to marginalization, exploitation, and abuse. Unless these groups are specifically mentioned in human rights treaties, they may be deprived of the protections and guarantees of the general children’s human rights agenda, including the Convention on the Rights of Persons with Disabilities (CRPD). For this reason children with disabilities are mentioned in a separate article in the CRPD. For them, as for all children, the assurance of their human rights, especially to health, survival, and an adequate standard of living, is critical.

There are an estimated 150 million children with disabilities in the world. More than 80 percent of them live in developing countries with little or no access to services, such as education.1

Many different experiences shape a childhood, including a child’s personal characteristics, gender, class, ethnicity, culture, religion, (dis)ability, socio-economic situation, location, family situation, environment, education, work, and sexual orientation. These experiences need to be taken into account when guaranteeing the human rights and fundamental freedoms of children with disabilities.

1 Committee on the Rights of the Child, General Comment No. 9: The Rights of Children with Disabilities. 29 Sep. 2006. UN doc. CRC/C/GC/9  
http://www.ohchr.org/english/bodies/crc/docs/co/CRC.C.GC.9.doc
EXERCISE 15.1: What Rights of Children with Disabilities Does the CRPD Affirm?

Objective: To review and understand the rights of children with disabilities affirmed by the CRPD

Time: 30 minutes

Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to paraphrase the paragraph in the CRPD Preamble, Articles 3, 4, and 7 in common language and give some examples of how that right could be enjoyed and make a difference for children with disabilities in their community.

2. Paraphrase:
Read the CRPD sections above aloud, pausing at each comma or paragraph to ask different groups for their paraphrase. Discuss the meaning of each section until everyone can agree on a paraphrase. Write the final paraphrase on chart paper.

3. Give examples:
Ask for examples of how these rights could be enjoyed and make a difference for children with disabilities.

Barriers to Children with Disabilities

Before Birth
• Poor maternal health and nutrition
• Poverty
• Inadequate prenatal care
• Prenatal screening and termination of pregnancy

At Birth
• Euthanization
• Denial of appropriate medical treatment
• Risk of rejection by parents
• Institutional placement

After Birth
• Institutional placement
• Isolation in the home and isolation from the community
• Denial of the right to education and many other human rights
• Risk of continual medical treatments, some painful and unnecessary
• Denial of the right to participate in decisions that effect their lives
4. Discuss:
How can these articles of the CRPD be used to create social change or impact national policy or local/community decision-making?

Realizing a Child’s Rights and Freedoms

A child’s enjoyment of his or her rights and freedoms depends on many interrelated factors. The following factors may influence the extent to which a child with a disability is excluded within their particular culture and context:

- **Prejudice and ignorance**: negative attitudes and false beliefs are by far the main barriers in all cultures and contexts;
- **Gender**: female children with impairments are more likely not to survive, to be abandoned, to be discriminated against, to be excluded from education, to be deemed un-marriageable and to be excluded from motherhood and general participation in their society;
- **Poverty**: where communities lack access to basic resources, families having members with disabilities are frequently the poorest and most marginalized. Even the very poorest families initially try to care for and protect their child, but they often become trapped in a cycle of poverty and exclusion due to negative beliefs and behaviors and a lack of information, knowledge, skills, and resources;
- **Crisis situations**: children in particularly difficult circumstances such as natural disasters, armed conflict, and refugee situations are particularly vulnerable to exclusion.

The CRPD and the **Convention on the Rights of the Child** (CRC) provides the legal framework for guaranteeing children access to their human rights, but many factors influence the extent to which children with impairments realize those rights:

- attitudes and behaviors of others towards them (e.g., parents, teachers, neighbors, other children)
- satisfaction of basic needs (e.g., survival, food, shelter, stimulation)
- international and national policies which include or exclude them
- accessibility of the physical environment (e.g., home, school, community)
- access to supports for their physical, social, mental, communication, and personal development (e.g., basic aids and equipment, assistance, health and education services, access to early childhood care and education).

Child-Centered Approach to Rights Programming

It is important to remember that children with disabilities, like all children, have the right to be active participants in decisions that affect them. Some key considerations for child-rights programming using a child-centered approach are:

- Consider children’s **best interests**;
- **Listen** to children with disabilities;
• **Challenge your own** and others’ **assumptions** about the needs and perspectives of children with disabilities;
  - Don’t make assumptions about what children with disabilities can and cannot do;
  - Don’t make assumptions about the needs and perspectives of children with disabilities (ask them!);
• **Value diversity**
  - Consider differences between disabilities and abilities;
  - Seek to develop the child’s abilities and competencies;
• **Consider the child as a whole** and the whole range of his or her development and needs
• **Analyze** the situation of the child as a whole in its broader context of family and community;
• **See children with disabilities as “social actors”** who are involved in decision-making.

### EXERCISE 15.2: Attitudes, Beliefs, and Views on Diverse Childhoods

**Objective:** To identify common attitudes, beliefs, and views on diverse childhoods

**Time:** 40 minutes

**Materials:** Handout; chart paper and markers, or blackboard and chalk

1. **Reflect/Analyze:**
   Break into small groups and ask them to discuss the first and second column of Handout 15.2.
   - What are 5 common **negative beliefs** and attitudes in your country about children with disabilities and their childhood?
   - What are 5 common **positive beliefs** and attitudes in your country that support children with disabilities and their childhood?
   - Ask groups to record their answers on chart paper in the same format as Handout 15.2.
   - After brainstorming on the first and second column, ask groups to reflect on both columns and now discuss the third column;
   - If you listen to children with disabilities, what are their concerns and opinions regarding opportunities and programs available to them (programs for all children and/or programs for children with disabilities)? How do positive and negative beliefs (Columns 1 & 2) impact their opportunities?
   - Invite groups to post their charts on the wall. Have participants move around the room quietly reading the charts of groups and noting common ideas and differences.

2. **Discuss:**
   Reconvene as a larger group to discuss reflections. After the reflections, summarize the session and review some of the key points from Handout 15.2:
   - How do the differing abilities of children with disabilities impact these views (e.g., children with visual impairments, psycho-social disabilities, multiple disabilities)?
   - How does age affect expectations (e.g., for toddlers, youth, young adults)?
   - How does gender affect expectations for children with disabilities?
   - How is this cycle of oppression/exclusion strengthened through individuals and society? How do cultural expectations influence children with disabilities?
   - In challenging our assumptions about children with disabilities, how can we promote a child-centered approach (e.g., listening to children, allowing them to be active participants involved in decision-making)?
   - How can this cycle can be broken through program interventions?
Children’s rights have foundations in provisions of international law. The Universal Declaration of Human Rights (UDHR)\(^2\) Article 25, the Convention on the Rights of the Child (CRC)\(^3\) and the 1993 UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules)\(^4\) address the rights of children with disabilities.

The 1948 Universal Declaration of Human Rights (UDHR) mentions children in Article 25 and 26. Article 26 states that motherhood and childhood are entitled to special care and assistance and that all children, regardless of whether they are born in or out of wedlock, shall enjoy the same social protection. Article 26 entitles everyone to equal access to education and allows parents the right to choose the kind of education given to their child.

The 1989 CRC, the most universally ratified of all human rights treaties (only the USA and Somalia are not States Parties), lays the foundation for and defines the many rights that

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2  See http://www.unhchr.ch/udhr/lang/eng.htm  
3  See http://www.ohchr.org/english/law/crc.htm  
4  See http://www.ohchr.org/english/law/opportunities.htm
the CRPD affirms. The CRC provides an over-arching framework for children’s rights and makes special mention of children with disabilities in Articles 2 and 23. It is important to remember, however, that every article in the CRC that refers to “the child” applies also to the child with disabilities. This inclusion marks an important shift in thinking towards a “rights-based approach,” holding governments legally accountable for failing to meet the needs of all children. The CRC creates a new vision of children as bearers of rights and responsibilities appropriate to their age, rather than viewing them as the property of their parents or the helpless recipients of charity.

The CRC has special provisions for children with disabilities. Article 2.1 prohibits discrimination on various grounds, including disability, and Article 23 sets out the right to special care, education, and training. Children’s rights cover four main aspects of a child’s life that apply equally to children with disabilities: the right to survive, the right to develop, the right to be protected from harm, and the right to participate.

- **Survival rights:** the right to life and to have the most basic needs met (e.g., adequate standard of living, shelter, nutrition, medical treatment);
- **Development rights:** the rights enabling children to reach their fullest potential (e.g., education, play and leisure, cultural activities, access to information and freedom of thought, conscience and religion);
- **Participation rights:** rights that allow children and adolescents to take an active role in their communities (e.g., the freedom to express opinions, the freedom to have a say in matters affecting their own lives, the freedom to join associations). Respecting a child’s opinion (Article 12) is especially important as it gives children the right to a voice in all matters concerning them (e.g., kinds of treatment for disabled children);
- **Protection rights:** rights that are essential for safeguarding children and adolescents from all forms of abuse, neglect and exploitation (e.g., special care for refugee children and protection against involvement in armed conflict, child labor, sexual exploitation, torture, and drug abuse).

The 1993 UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules) address the rights of children and their families in Rule 2 (medical care), Rule 6 (education), which includes very young children with disabilities, and Rule 9 (family life and personal integrity).

Rule 2 states that infants and children should especially have access to the same level of medical care that others have. Rule 9 states that persons with disabilities should be enabled to live with their families. States should encourage the inclusion in family counseling of appropriate modules regarding disability and its effects on family life. Respite-care and attendant-care services should be made available to families that include persons with disabilities. The Education Rule 6 states that general education authorities are responsible for the education of people with disabilities in integrated settings and encourages the active involvement of parent groups and organizations in the education process. Special attention is given to very young children with disabilities and populations at risk for double discrimination.

It is important to remember that all international treaties apply, protect, and enable **all**, including infants, children, and youth with disabilities.
Regardless of ethnicity, economic status, or class, all parents are distressed when they learn that their child has a disability. The differences among them are very great, however, when you compare their beliefs and the resources and supports available to them. Traditionally, families, including grandparents and siblings, carry the responsibility for providing care to children with disabilities with little to no help from society. To effectively advocate for services, parents need to understand their rights and the rights of their child, as defined by CRC and CRPD.

Support for the Family

- **Raise Community Awareness**: Dispel myth and stigma associated with disability.
- **Provide Information and Resources**: Build the knowledge and skills of family members, peers, and the community.
- **Provide Access to Rehabilitation and Habilitation**: Provide access to adequate medical care and equipment, as well as to support and services for children with disabilities.

**One Parent’s Story**

I am a parent of a disabled child. I am also a community worker with a good understanding of our early intervention program.

I felt great about this opportunity to increase awareness about disability (the START Program at the Sunshine Centre). I also wanted to help and support the parents of disabled children in this area. Often such parents do not trust people who have not had the same experiences. I know they can feel very isolated and ignored. I understand from my own experience that many of them do not get support from their families because there is no understanding of the needs of their disabled children.

Many fathers of the disabled children do not give their support. My husband had great difficulty in accepting that our son was disabled. I was not supposed to walk in the street with my child. His father could not believe that other people could see the beauty of this child. I struggled because he refused to give me any money for the special food our child needed.

I know how lonely and frightened these parents can feel. I worried about who would be responsible for our child if something happened to me. I even believed it would be the best thing if my child died before me.

I became a community worker because I saw how parents of disabled children really need support. I knew that with training, parents could help each other. They do not need people who feel ashamed of disabled children. They need to talk to someone who can understand that even though the child is disabled, he is still a human being. He does not have a disease that can affect other people.5

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As the example above demonstrates, raising community awareness and providing supports can enable a child with a disability to gain the skills necessary to participate in education, care for themselves, and contribute to society.

For more information on a child’s right to education, see Part 2, Chapter 13, “The Right to Education,” p. 165.

**THE CHILD’S RIGHT TO PARTICIPATE**

The child participation is key to enabling children’s rights. Children have the right to express their views and be consulted in matters that may affect them. This should happen at levels of policy, community, family, and self. Once children or young adults have the skills to communicate their wants and needs, it is vital that they contribute to decisions made on their behalf.

A rights-based approach to participation means putting girls and boys from all backgrounds and disability types, including intellectual and psychosocial disabilities, at the center of human rights policy and programming. This approach also recognizes children with disabilities as right-holders and members of society and holds governments accountable for ensuring the rights of all their citizens, including children with disabilities.

**How to Achieve Children’s Participation**

**Social and Political Movements**
- Children form their own movements and organizations to claim their rights with support from adults;
- Change the power relations between children and adults;
- Enable children to become democratic citizens.

**Human Rights**
- Promote children’s civil rights (e.g., expression, thought, information, organization);
- Recognize children as rights holders.

**Child Development**
- Develop children’s abilities, confidence, and independence;
- Develop children’s ability to protect themselves;
- Improve children’s locus of control, level of empowerment, and learning.

**Development**
- Understand children better;
- Develop better programs and policies for children.

According to Equal Opportunity Theory, social policies can be put in place to empower and protect persons with disabilities. But until we teach children the skills (i.e., increase their capacity) to make decisions, provide them with opportunities to make decisions, and respect the choices they make, equality and inclusion, which are principal tenets of the CRPD, will not be

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achieved. It is not only a matter of making choices, but also of being empowered to act, subject to individual circumstances, toward pursuing one's own ends in life in the community.

Social Policies that Protect and Empower Individual Freedom

Capacity
Teach children the skills necessary to make decisions and be independent

Opportunity
Provide children with opportunities to make decisions affecting their lives

Respect
Respect the opinions and choices children with disabilities make regarding their lives

Equal Opportunity Model
Mathieu (1998)

HUMAN RIGHTS LAW THAT GUARANTEES CHILDREN’S PARTICIPATION

Primary Article on Participation in the Convention on the Rights of the Child:
- Article 12: the general principle that children have the right to express their views freely in matters affecting them and that their views should be given due weight in accordance with their age and maturity.

The right to participation is also explicitly or implicitly expressed in many other CRC articles:
- Article 5: parental supervision of direction and guidance in accordance with respect for children's evolving capacity
- Article 9: non-separation of children from families without the right to make their views known
- **Article 13**: the right to freedom of expression
- **Article 14**: the right to freedom of conscience, thought and religion
- **Article 15**: the right to freedom of association
- **Article 16**: the right to privacy
- **Article 17**: the right to information
- **Article 29**: the right to education that promotes respect for human rights and democracy
- **Article 31**: the right to play.

### Primary Article on Participation in the CRPD

**Article 7**: states parties should take all necessary measure to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children; the best interests of the child is the primary consideration; they have the right to express their views freely on all matters affecting them, given due weight to their age and maturity; and are to be provided with disability and age-appropriate assistance to realize their rights.

The right to participation is also expressed in many other the CRPD articles, which build upon the CRC:

- **Preamble**: children with disabilities should have the same human rights and fundamental freedoms as other children as included under the provisions of the CRC;
- **Article 3**: respect for evolving capacities of children with disabilities and their right to preserve their identities;
- **Article 4**: children with disabilities should be consulted with and involved in the development of legislation and policies to implement the CRPD.

### EXERCISE 15.3: Describing Good Practices and Overcoming Resistance to Children’s Participation

**Objective**: To describe good practices of child participation and identify common forms of adult resistance to child participation and strategies to overcome resistance

**Time**: 50 minutes

**Materials**: Handout; chart paper and markers, or blackboard and chalk

1. **Small Group Work**:
   - Break participants into small groups and share experiences of working with children and young people with disabilities as partners in their programs/projects. Ask them to focus on those that have resulted in positive outcomes;
   - Ask individuals to present some of their key examples. After each presentation, ask their reasons for selecting those particular examples;
   - Using Handout 15.3, identify and record adult resistance to child participation and ways of overcoming adult resistance toward the participation of children with disabilities (e.g., in family, schools, communities, local government);
   - Analyze the answers to identify the common resistance and strategies for overcoming resistance;
   - Reflect on resistance and how it varies: for different types of disability, for girls or boys, for school-going or non-school-going children, and in rural and urban settings.
2. Discuss:
   - Ask participants to share their outcomes.
   - Encourage them to cite positive personal experiences as inputs into the process of overcoming resistance.

**Handout 15.3: Adult resistance to child participation and overcoming resistance**

<table>
<thead>
<tr>
<th>Family</th>
<th>Adult’s resistance to child participation</th>
<th>Overcoming adult resistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Workplace</td>
<td></td>
<td></td>
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<tr>
<td>Local Governance</td>
<td></td>
<td></td>
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<tr>
<td>Within own organization or NGO</td>
<td></td>
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<tr>
<td>Add more…</td>
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<td></td>
</tr>
</tbody>
</table>
EXERCISE 15.4: Children with Disabilities as Partners in Programming

Objective: To identify good practices for enlisting the participation of children with disabilities in the program cycle or parts of the program cycle and to identify ways for strengthening children with disabilities participation in programs and projects.

Time: 60 minutes

Materials: Handout, chart paper and markers or blackboard and chalk

1. List:
   Ask participants to share good examples of working with children with disabilities as partners in programs and to identify the gaps in their interventions. List the gaps on chart paper or board.

2. Small Group Work:
   • Break into small groups and discuss the following questions about their gaps:
     ■ Are children with disabilities (including children with intellectual disabilities) consulted and involved: are their views incorporated into stages of programming/the project cycle?
     ■ Is relevant and child/ability-friendly information provided?
     ■ Are the views of different groups of children (different disabilities/ages) taken into consideration?
     ■ Will the project empower children and/or adults to claim the rights of children (as in the CRC) and the rights of persons with disabilities (as in the CRPD)?
   • While still in their groups, ask participants to focus their discussion on ways to strengthen the participation of children with disabilities in programs and projects. What are some key lessons:
     ■ on empowering children with disabilities?
     ■ on encouraging adults to realize the rights of children with disabilities?

3. Discussion:
   • Bring all groups together to share ideas. Summarize by going through some of the program and project cycle and identifying a few key elements in similar and contrasting ways to strengthen the participation of children with disabilities. You may refer to the information below to better understand some positive outcomes of working with children and young people with disabilities.

POSITIVE OUTCOMES OF WORK WITH CHILDREN AND YOUNG PEOPLE WITH DISABILITIES

These examples point to key lessons on empowering both children and adults working together to realize child rights.

Recognition of Children as Social Actors
   • Parents and community members develop respect for the views and rights of children with disabilities, thereby increasing their status and voices;
   • Children with disabilities are recognized as social actors who make positive contributions to local communities and society;
   • Children with disabilities bring about attitude changes amongst adults, thus challenging discrimination in the family, school, and community.
Children as Right Holders

- Children with disabilities are empowered to address violations of rights and claim their rights;
- Educational performance of children with disabilities is improved;
- Self-esteem, confidence, and resilience of children with disabilities are enhanced;
- Enthusiasm of children with disabilities to address issues for the benefit of their peers and community is developed;
- Communication, negotiation, and teamwork skills are increased;
- Values, skills, and knowledge of democratic functioning among children with disabilities are enhanced;
- Girls and boys with disabilities through knowledge of their own rights and recognition of the value of their participation are empowered.

Working with Children in Program Development

- Opportunities are created for children with disabilities to participate in planning, decision-making, reporting and legal amendments at different levels of their community and government;
- Children with disabilities are able to express their own perspectives, their understanding of issues, problems, analysis, solutions, and priorities, which often differ from those of adults.

Program Outcomes

- Reduction in discrimination against children with disabilities;
- Increased inclusion in the community and school;
- Persuading the local community to take action; improve attitudes and access to the home, community, and school;
- Children with disabilities are able to protect themselves from abuse.

Attitudes and Support of Adults

- Adults are more accepting of children’s representation and views at the community and district level;
- Social changes can be seen in adults’ and peers’ attitudes and mindsets;
- Adults are being held more accountable to address child and disability rights violations and to provide accessible, quality services to all children;
- Increased commitment amongst adults to work with and for children with disabilities.7

Throughout this chapter you have learned how children have the right to participate fully and express their views in matters that affect them, as well as how adults can be resistant to their participation for many reasons. You have discovered that children’s rights need to not only be protected, but promoted as well. And most importantly, that children can actively participate as partners in programming, leading to many positive outcomes, such as empowerment, social action and inclusion, and the reduction of discrimination. Because the rights of children with disabilities are vulnerable to abuse, it is the responsibility of human rights law and society to ensure these rights are upheld.

EXERCISE 15.5: Making a Commitment

Objective: To emphasize and examine that the human rights of children with disabilities involve both rights and responsibilities

Time: 30 minutes

Materials: Chart paper and markers or blackboard and chalk

1. Action:
   • Ask if, after learning about the human rights of children with disabilities, the group members are ready to think about taking concrete action.
   • Acknowledge that, although there is still much planning and information gathering to do, commitment to creating change is very important.
   • Explain that you would like to ask each participant to name one individual action, however small, that she or he is willing and able to take in the next month to promote the rights of children with disabilities.
   • Record the commitments on chart or board to distribute a summary of actions to all participants after the training.

The rights of children with disabilities are the same as those of everyone else. Children with disabilities are entitled under the CRC and the CRPD to the same human rights and fundamental freedoms as all other children and as all other persons with disabilities. States Parties and organizations are obligated to involve children with disabilities and enable them to attain their rights and freedoms. The active involvement of children with disabilities in policy and programming is not only an obligation, but also a benefit both to the child and the whole community.


USEFUL RESOURCES ON THE HUMAN RIGHTS OF CHILDREN WITH DISABILITIES

• International Save the Children Alliance: http://www.savethechildren.net/alliance/index.html
• Lessons for Including Children in Policymaking: http://www.savethechildren.net/alliance/resources/12lessons.pdf
• Mithaug, Dennis. E., “Your right, my obligation?” The Journal of the Association for Persons with Severe Handicaps, 23(1), 41-43 Spr 1998
• Save the Children UK: http://www.eenet.org.uk/bibliog/scuk/scuk_home.shtml
• The Sunshine Centre Association (START Distance Project): http://www.sunshine.org.za
• UNICEF: http://www.unicef.org/crc