A World Fit for ALL Children:

Including the Rights of Children with Disabilities in the UN Convention on the Rights of the Child
National Plans of Action

Guidelines for Inclusion

March, 2003

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**INTRODUCTION & BACKGROUND: The United Nations Convention on the Rights of the Child (UNCRC) and the World Fit for Children (WFfC)**

In 1991 the historic World Summit for Children culminated in the ratification of the United Nations Convention on the Rights of the Child (UNCRC). This Convention, ratified by every government in the world (with the exception of Somalia and the United States), serves as an international human rights treaty that calls for the development of national policies and programmes to ensure that all young people (defined as less than 18 years of age) get the chance to grow up in a protective, nurturing and stimulating environment, right from the beginning. In May 2002 the United Nations General Assembly Special Session (UNGASS) on Children was held in follow-up to the 1991 Summit and brought together all signatory governments to reaffirm their commitment to the UNCRC and to address emerging issues fundamental to securing the human rights of children. From this meeting resulted A World Fit for Children (WFfC); a document that outlines more specific obligations for achieving the commitments enshrined in the UNCRC.

Today governments are in the process of developing National Plans of Action (NPAs) to implement the commitments agreed upon over a decade ago. These plans of action will describe how each government will address children’s rights domestically and will certainly impact on how governments decide to invest in children. The NPAs are currently in the process of being drafted by respective governments and will be presented to the United Nations by the end of 2003. Governments will then be expected to implement their plans over a five-year period and report to the UN Committee on the Convention of the Rights of the Child throughout the process.

**“All Children, All Rights”: Ensuring that Children with Disabilities Are Effectively Included in the NPAs**

Over the last 12 years, since initial National Plans of Action were developed and implemented, experience has shown that all too often the rights of children with disabilities are forgotten or ignored. Supporting children with disabilities and their families is generally viewed as a separate consideration altogether and the processes for incorporating their needs and rights is not viewed in tangent with those of the needs and rights of children more generally. These guidelines have been developed to ensure that children with disabilities are not left out in this round of NPAs. It must be stressed, however, that the view here is not to create separate systems for children with disabilities but to promote inclusion as the primary and most effective vehicle for properly addressing the rights of all children together.

A number of guidelines have already been developed, by Save the Children, The Child Rights Information Network (CRIN), Children’s Rights Caucus, and the NGO Group for the Convention on the Rights of the Child, describing how to get involved in the NPA process, but few have adequately addressed the rights of children with disabilities in a way that promotes and protects inclusion. To complement existing guidelines, this document has been created to assist all civil society organizations to participate in consultations and preparations of NPAs. It is intended to present suggested guidelines for how to include the rights of children with disabilities into action plans in a way that ensures that all children are supported to develop according to their potential, grow up among their family members, and live in their communities - in safety, security, and with affection.
Planning for All Children Means Planning for Inclusion

Inclusion is about being appreciated, valued and respected in the social, economic, political and cultural life of the community; being recognized for the abilities and talents one does have; being given the same opportunities and encouragement to develop and grow into the kind of person one chooses; and, developing trusted relationships and friendships to develop to the best of one’s ability and create the kind of life that one values.

In practical terms inclusion is:

- targeted at the ways in which communities, systems and societies are organized;
- about transforming communities, systems and societies to be diversity-sensitive;
- a sustainable vehicle for achieving human rights.

Inclusion is not simply about opening the doors to our communities, schools, and workplaces to let in people who are marginalized. Inclusion is about transforming our communities so that they enable the participation of all people according to their will and capacity. When these changes are achieved, we help create a better world for everyone. Investing in the inclusion of persons with an intellectual disability and their families can help reduce poverty, increase democratization and foster social cohesion, stability and peace. We can demonstrate how engaging society's most marginalized members can help to build consensus, develop common values and transform communities.

Realizing the human rights of people who have an intellectual disability and supporting their full participation and contribution to their communities depends on addressing the causes of exclusion that lie in economic, social, political and cultural policy; an exclusion that also speaks to the marginalization of many other groups. Getting children who have intellectual disabilities into school is only part of the challenge, we must consider reorganizing curricula, reducing class sizes and adapting the materials and resources used both in teacher training as well as those used in the classroom. When people are active participating members of society their value and humanity are recognized by those who know them.

Of 600 million people with disabilities:

- It is estimated that 30 – 40 % of households worldwide are caring for a member with a disability;
- An estimated 80% live in a developing country;
- Less than 2% of children receive any formal education;
- Disability increased in the past 10 years as a result of famine, drought, malnutrition, war and natural disasters.

Overcoming exclusion requires the elimination of physical, social, cultural, and economic barriers that discriminate against children with intellectual disabilities.

Under the WFfC, governments have committed to four main objectives that directly affect the lives, rights, inclusion and well being of children with disabilities and their families. In the following section we have identified various ways that the NPA s could be designed to include all children.
**WFfC OBJECTIVE (1): PROMOTING HEALTHY LIVES**

**REDUCING THE SOCIAL AND ECONOMIC POVERTY OF CHILDREN WITH DISABILITIES AND THEIR FAMILIES TO PROMOTE HEALTHY LIVES**

Throughout the world, people with disabilities and their families share a common experience of being devalued by their communities and societies. An estimated 30 - 40% of households worldwide have a member with a disability and since families are the primary support systems for individuals with a disability they generally face higher instances of ill health due to increased stress and insecurity, higher health-related costs for their family member with a disability, labour force exclusion, isolation from community support, and poverty than do their neighbouring households. Women in particular are impacted as they take on the majority of care-giving responsibilities.

Consider some of the factors contributing to higher instances of poverty for children and youth with disabilities and their families:

- Decreased exposure to educational and vocational training coupled with undervaluing of the abilities of people with disabilities result in fewer opportunities for self-sustaining employment;
- Care-giving responsibilities result in lost income for family members caring for a person with a disability;
- Increased medical costs associated with disability, including travel and access costs;
- Overall increased vulnerability to ill-health and economic poverty;
- Increased social vulnerability to abuse and exploitation;
- Social isolation of persons with disabilities and their family members caused by negative social attitudes.

**Figure 1: The Poverty Cycle for People with Disabilities and their Families**

National Plans of Action can address these issues by:

- supporting families to care for their members with a disability at home, in the community;
- investing in inclusive education to ensure that children with disabilities gain a good quality education in an equal learning environment among their peers (see Inclusive Education);
- creating family forums where the voices of families are recognized, heard and implemented;
- raising awareness about issues affecting people with disabilities and their families in the media and through other mechanisms;
- raising awareness about the knowledge of families since families know their family members best;
- supporting the development of a family policy agenda;
- providing adequate financial support to families with a child with a disability to cover additional costs associated with disability;
- developing mechanisms to provide labour market access and vocational training for people with disabilities.

**HEALTH & RECREATION**

Disability is often equated with ill health and the cycle of finding a 'cure' or 'treatment' can result in families despairing because of their children; well-meaning terms of 'rehabilitation' which are designed again to portray the need to 'fix' the child add to the stigmas and stresses. While the need for appropriate services and systems must be in place, the argument of attitudinal change is also very critical. In fact the United Nations preamble to the Standard Rules defines ‘Handicap’ as "The relationship between an individual and their environment".

Health is increasingly understood as more than an absence of disease or illness and that health promotion focuses on providing individuals, groups and communities with the tools to exercise greater control over the resources and strategies necessary to achieve their health and well being. In many places there is no legislation or entitlement to disability supports -- but there is to health care. Thus, the incentive to obtain medical diagnosis is a way of obtaining supports. There are several barriers in health systems for children with disabilities and their families including:

- attitudes
- physical barriers
- equation of disability with ill health and disease
- lack of adequate planning and coordination supports
- rationing health care
- training of medical personnel

We would also be remiss if we didn’t point out the threat of biotechnology and the opinions that place little value or worth on the lives of children with disabilities. Not only do these attitudes lead to exclusion, they now may also have the capacity to prevent...
children whose lives are deemed ‘worthless’ and a ‘burden’ to even be born and thus prevent the birth of children who have innate gifts, talents and human-ness.

A World Fit for Children identifies the need for strategies and actions to “provide access to appropriate, user-friendly and high-quality health-care services, education and information to all children” (11B.37.2) and to “promote physical, mental and emotional health among children, including adolescents, through play, sports, recreation, artistic and cultural expression” (11B.37.19).

National Plans of Action can address these issues by:

• providing timely access to appropriate, user-friendly and high-quality, diverse and flexible health-care services that accommodate all unique needs which are coordinated to respond to particular health and support needs as defined by families;

• addressing the discrepancies in health services availability, access and adequacy for children with and without disabilities, and being child friendly and partnering with parents and the community;

• creating models of inter-departmental / governmental collaboration that include children with disabilities and their families;

• ensuring that diagnosis, developmental screening, readiness tests, and performance assessments identify needs for (early) intervention and family support to prevent the streaming of individuals into special programs and congregated settings;

• basing needs assessments on a comprehensive view of the child and family rather than a functional evaluation or medical diagnosis;

• sharing control between decision-makers and families and having the support to do so;

• using a health promotion instead of disability prevention approach;

• strengthening and supporting community capacity to include and support children with complex medical needs;

• researching and implementing supported health planning;

• providing access to direct interventions for children in order to meet their unique needs;

• redrawing the network of supports to families and children in health planning to encompass inclusive health care, child and family services, schools, community organizations and other generic resources:

  o For children and families this means a fuller life in the community- with good planning and access to good services.

  o For communities this means new capacities to accommodate and support diversity.

  o For health care institutions and governments this means the goal of securing more cost effective options can be achieved.

“Wewill take all measures to ensure the full and equal enjoyment of all human rights and fundamental freedoms, including equal access to health, education and recreational services, by children with disabilities and children with special needs to ensure the recognition of their dignity, to promote their self-reliance and to facilitate their active participation in the community.”

Article23 - Children with Disabilities, UNCRC
Health is also categorized in terms of recreation. Recreation plays an important role in fostering active citizenship, social inclusion, improving physical and mental health, increasing self-esteem and encouraging better academic performance. Barriers faced by children and youth must be acknowledged and eliminated to enable all children to belong to their community and participate in physical activities and recreation. For all children and youth with disabilities to be fully engaged in these opportunities, a broad understanding of accessibility must be developed, one that is beyond physical terms only.

National Plans of Action can address these issues by:

- designing physically accessible play areas;
- developing recreational games that are inclusive of all children and their needs;
- sponsoring recreational programs with a clear policy to include all children and accompanied by adequate supports to assist all children to benefit from play.

**EARLY CHILDHOOD DEVELOPMENT**

The Convention on the Rights of the Child acknowledges that childhood is a unique period in the life of all persons and as such is entitled to special care and assistance. “A world fit for all children is one in which all children get the best possible start in life and have access to a quality basic education, including primary education that is compulsory and available free to all... and have ample opportunity to develop their individual capacities in a safe and supportive environment.”


In recent years there has been an increased awareness and understanding of the importance of investing in development in the early years and that the path of life-long learning begins in early childhood. However, there is grave concern that children with disabilities and other marginalized children are at risk of being excluded from early childhood investments based on assumptions about healthy child development that uses normative developmental milestones such as age appropriate motor and language skills as the benchmark. These assumptions are highly detrimental to the equality of children with disabilities and other marginalized children who have witnessed first hand the exclusion and negative treatment that results.

National Plans of Action can address these issues by:

- promoting and adopting an alternative approach to healthy child development that respects the inherent value of all children and recognizes their unique developmental paths and contributions;
- developing and promoting guidelines for inclusive early learning and development that reject discrimination in access on the basis of disability;
- designing and evaluating curricula and early learning and care environments that ensure each child's physical, emotional, intellectual, spiritual and social well-being; promotes diversity; reduces disparity; develops capacity; and enhances learning;
• ensuring that early childhood development policies, practices and programs are geared to meeting the unique needs of every child and family and provide the supports necessary to make early learning and care inclusive, flexible and responsive;

• developing and distributing practical tools and approaches to inclusive policy and program development and delivery;

• ensuring that investment plans by governments and communities for early childhood development include specific measures of inclusion, with investments in resources and leadership that can create a culture that celebrates all children.

Acting on these recommendations will begin to enable the achievement of the following goal outlined in The World Fit for Children - “expand and improve comprehensive early childhood care and education, for girls and boys, especially for the most vulnerable and disadvantaged children.” B. 39 (a)

**WFfC OBJECTIVE (2): PROVIDING QUALITY EDUCATION**

**INCLUSIVE EDUCATION**

The World Health Organization (WHO) estimates that less than 2% of students with disabilities receive any formal education and UNICEF ascertains that only 1% of girls with disabilities attend any school at all. Exclusion from mainstream, high-quality education means fewer opportunities for employment, a higher vulnerability to abuse, and isolation from relationships that teach how to value and be valued by others.

National Plans of Action can address these issues by:

• providing teachers with the necessary education, training, information, and knowledge about how to include children with disabilities and provide them with education;

• designing the curriculum to be diversity- and disability-sensitive to help create an inclusive culture for both students with disabilities and their peers;

• designing and evaluating the curricula in a way that accounts for different learning styles, and for students’ unique developmental paths;

• designing classrooms in a way that ensures that students have access to the supports they need to be able to take advantage of inclusive educational services;

• ensuring that the eligibility process for determining access to funding needs to value children and youth, enable identification of needs without further stereotyping and minimizing the potential of the child;

“Promote innovative programmes that encourage schools and communities to search more actively for children who have dropped out or are excluded from school and from learning, especially girls and working children, children with special needs and children with disabilities, and help them enrol, attend, and successfully complete their education, involving governments as well as families, communities and non-governmental organizations as partners in the educational process…”

WFfC, para 40.2, pg.16
• ensuring that departments of health, education, social services and other related departments work in a coordinated, collaborative, integrated, flexible and holistic fashion to accommodate the needs of all children;

• focusing, wherever relevant, individual assessments, planning and placement processes on individuals and families in order to value and recognize the knowledge of families;

• ensuring the full recognition of different learning styles and developmental paths of children in curriculum, resourcing, pedagogical practice and technical support.

WFfC OBJECTIVE (3): PROTECTING AGAINST ABUSE, EXPLOITATION AND VIOLENCE

PROTECTION FROM ABUSE, NEGLECT, AND EXPLOITATION AND VIOLENCE

Children have the right to be protected from all forms of abuse, neglect, exploitation and violence. Children and youth with disabilities are more likely than other children to be physically and sexually abused and violence against people with disabilities is recognized as a serious and pervasive problem.

National Plans of Action can address these issues by:

• raising awareness about violence and abuse, individual rights, personal safety and protection, rights over one's own body, and other related topics by developing plain language resources, holding participatory community-based sessions, or through other appropriate means;

• developing tools, guides and training sessions for law enforcement personnel and the legal community to raise awareness about appropriate and sensitive methods for interviewing a victim who has a disability;

• supporting community forums amongst community members, law enforcement personnel and legal advisers to develop strategies for protecting personal safety and quickly and responsibly investigating a crime when it has been committed.

DEINSTITUTIONALIZATION

Families are not recognized as integral partners in the development of community services and supports. In some cases, recognition exists but this must be followed up by the provision and the development of supports that value the contributions of every child and his/her family. This might mean ongoing financial support to families in many cases, but again we need to see this as an investment rather than as an expense. This often leads to a vicious cycle; when families are not supported, are poor and already marginalized, children tend to enter into child welfare programs where available.

"The family is the basic unit of society and as such should be strengthened. It is entitled to receive comprehensive protection and support. The primary responsibility for the protection, upbringing and development of children rests with the family. All institutions of society should respect children's rights and secure their well-being and render appropriate assistance to parents, families, legal guardians and other caregivers so that children can grow and develop in a safe and stable environment and in an atmosphere of happiness, love and understanding, being in mind that in different cultural, social and political systems various forms of family exist."

Plan of Action A: Creating a world fit for children, para. 15
National Plans of Action can address these issues by:

- ensuring that all state and private run institutions are closed;
- supporting families to be able to care for their children with disabilities at home (see Supporting Families).

**WfFC OBJECTIVE (4): COMBATING HIV/AIDS**

The World Bank is currently in the process of conducting an international survey on the prevalence of HIV/AIDS among people with disabilities. Breaking down some of the main causes of HIV/AIDS infection are: a) unprotected sexual intercourse; b) drug abuse and needle sharing; c) sexual abuse; d) medical blood transmission; and, e) child prostitution.

For example:

- It is commonly assumed that people with disabilities do not engage in mature relationships involving sexual intercourse. This false assumption often leads to a neglect of people with disabilities when designing and implementing HIV/AIDS prevention teachings.

- Although no international statistics exist on the relationship between people with disabilities and sexual abuse, it is reported in the United States that, "For adults with cognitive impairments, reported rates for lifetime experience of sexual violence range from 25% to 67%" of which “About 95% of sexual violence episodes involve sexual contact”¹. In Canada, 40% to 70% of girls and 15% to 20% of boys with an intellectual disability are estimated to experience sexual abuse before the age of 18.²

National Plans of Action can address these issues by:

- creating plain language manuals and videos about HIV/AIDS and other sexually transmitted diseases (STDs) targeted at people with low literacy levels;
- ensuring that community awareness encompasses children with disabilities;
- ensuring that children with disabilities have equal access to anti-retroviral drugs;
- ensuring that children with disabilities orphaned by HIV/AIDS receive proper placement with relatives that can support them from thereon in;
- providing support to relatives caring for a person with a disability who has HIV/AIDS.

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How to Get Involved in the NPA Process  
Making Sure That Children with Intellectual Disabilities are Included in the Process!

By signing the United Nations Convention on the Rights of the Child (UNCRC), governments around the world have agreed that investing in children is crucial for securing a better future for everyone. They must now create a National Plan of Action, which will outline how they will fulfill their commitment to children.

People with disabilities and their families are often excluded from governments’ agendas for children even though the UNCRC makes a clear statement on the rights of children with disabilities. So, these guidelines have been created to offer suggestions for how people with disabilities, their families and organizations can play an active and important role in talking to government representatives to make sure that children with intellectual disabilities are not left out of the National Plans. Here are a few steps to help you get involved!!

You can get involved by...

☑️ Forming alliances, joining existing coalitions, creating knowledge amongst allies;
☑️ Seeking government partnerships;
☑️ Including youth and young children with disabilities (para. 59 of the Outcome Document which commits governments to work “in cooperation with relevant civil society actors, including non-governmental organisations working for and with children, as well as children, in accordance with their age and maturity, and their families”);
☑️ Asking about the timetable for preparation of a Plan of Action;
☑️ Proposing regular meetings and consultation as the Plan is being developed;
☑️ Approaching the NPA process from a rights-based perspective that uses the UNCRC as a framework;
☑️ Using other advocacy strategies;
☑️ Contacting sympathetic parliamentarians to raise the matter in Parliament and/ or write to ministers;
☑️ Using the media: publicizing your approaches to government, publicizing government lack of action, writing letters to newspapers;
☑️ Organising a conference or event and inviting a key minister to address the issue.

Some Questions to ask your Government:

Governments around the world have recommitted themselves to creating a world that is, indeed, fit for all children. By asking the right questions, raising awareness, and by holding governments accountable in the National Plans of Action they create, you can be part of making this commitment a reality.
1. Who is responsible within government for implementing the CRC and reporting under it?

2. Has your government:
   - Submitted initial and periodic reports to the Committee on the Rights of the Child (you can check this at www.unhchr.ch)?

3. What is the deadline for your country’s submission of the next report to the Committee on the Rights of the Child?

4. Has your government:
   - Developed a National Plan of Action (NPA) following the World Summit?
   - Developed a comprehensive NPA or a children’s strategy based on the whole Convention?
   - Submitted an end-decade review of progress since the World Summit (you can check this at www.unicef.org/specialsession/how_country/index.html)?

5. Who is responsible for the follow-up process to the Special Session?
   - Which government department(s)?
   - Which ministers?
   - Which key officials?

Let us know how the plan of action in your country includes or excludes children with disabilities. To do so, please contact us at the addresses on the front cover of this document or at info@cacl.ca.

Please refer to the following Inclusion Criteria below. These criteria can help you and your governments evaluate whether your country’s National Plans of Action are addressing issues affecting the lives of children with disabilities and their families in a way that promotes inclusion.

**YOUR VOICES COUNT, MAKE THEM HEARD!**
## WFfC Objective 1: Promoting Healthy Lives

### Supporting Families and Reducing Poverty:

- ✓ Have you developed mechanisms to support families to care for their children with disabilities at home?
- ✓ Are you investing in inclusive education so that all children gain a good quality education?
- ✓ Have you created family forums so that the voices of families are recognized, heard and implemented?
- ✓ Are you raising awareness about issues affecting people with disabilities and their families in the media and through other mechanisms?
- ✓ Have you developed a family policy agenda?
- ✓ Are you raising awareness about the knowledge of families since they know their family member best?
- ✓ Do families have access to government financial support to enable them to better care for their family member with a disability?

### Health:

- ✓ Are you providing timely access to appropriate, user-friendly and high quality, diverse and flexible health-care services that accommodate all unique needs?
- ✓ Have you addressed the discrepancies in health services availability, access and adequacy for children with and without disabilities?
- ✓ Are you creating models of inter-departmental / governmental collaboration that include children with disabilities and their families?
- ✓ Are you basing needs assessments on a comprehensive view of the child and family which is not limited to functional evaluation or medical diagnosis?
- ✓ Are you using a health promotion instead of a disability prevention approach?
- ✓ Are you strengthening and supporting community capacity to include and support children with complex medical needs?
- ✓ Are you researching and implementing supported health planning?
- ✓ Are you providing access to direct interventions for children in order to meet their unique needs?
- ✓ Are you redrawning the network of supports to families and children in health planning to encompass inclusive health care, child and family services, schools, community organizations and other generic resources?
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<tr>
<th>Recreation:</th>
<th>Yes</th>
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<tr>
<td>✓ Have you designed physically accessible play areas?</td>
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<td>✓ Have you developed recreational games that are inclusive of all children and their needs?</td>
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<td>✓ Are you sponsoring recreational programs that have a clear policy to include all children and are accompanied by adequate supports to assist all children to benefit from play?</td>
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<th>Early Childhood Development:</th>
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<td>✓ Have you designed and evaluated curricula and early learning and care environments that ensure each child’s physical, emotional, intellectual, spiritual and social well being; promotes diversity; reduces disparity; develops capacity; and enhances learning?</td>
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<td>✓ Are you ensuring that early childhood development policies, practices and programs are geared to meeting the unique needs of every child and family and provides the supports necessary to make early learning and care inclusive, flexible and responsive?</td>
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<td>Inclusive Education</td>
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**WFfC Objective 3: Protecting Against Abuse and Exploitation and Violence**

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<tr>
<th>Deinstitutionalization:</th>
<th>Yes</th>
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<td>✓ Are you raising awareness about violence and abuse, individual rights, personal safety and protection, rights over one’s own body, and other related topics by developing plain language resources, holding participatory community-based sessions, or through other appropriate means?</td>
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<td>✓ Have you supported community forums amongst community members, law enforcement personnel and legal advisers to develop strategies for protecting personal safety and for quickly and responsibly investigating a crime when it has been committed?</td>
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**WFfC Objective 4: Combating HIV/AIDS**

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<th>HIV/AIDS Awareness and Prevention:</th>
<th>Yes</th>
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<td>✓ Have you created plain language manuals and videos about HIV/AIDS and other sexually transmitted diseases (STDs) targeted at people with low literacy levels?</td>
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<td>✓ Do community awareness programs and documents include children with disabilities?</td>
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<td>✓ Are you providing equal access to anti-retroviral drugs to children with disabilities?</td>
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