



**Draft Comments
Of
The International Save the Children
Alliance
On
the Draft Comprehensive and Integral International
Convention on the Protection and Promotion of the
Rights and Dignity
of Persons with Disabilities
May 2004**

While many of the experiences of disabled adults and children and young people are similar, they are not the same. While parents and children share joint concerns their interests are not the same. It is not appropriate that the concerns or interests of children and young people are simply subsumed under those of adults or parents.

Too often the rights of disabled children are violated and disregarded. In order to ensure that the rights of disabled children and young people are included in the proposed Convention, it is imperative that their different perspectives are well reflected and made explicit in the text. The new Convention offers a unique opportunity to assert and codify those rights, and place explicit obligations on governments to take action to make them reality.

Save the Children is an international child rights organisation fighting for the rights of disabled children like all children. We look forward for a world, which respects and values disabled children like all children.

Based on our experience in child rights and child participation we consider it to be our duty to take part in the shaping of the new Convention. We base our input on what disabled children as rights-holders do prioritise to have their rights met like all children and to promote an inclusive society.

(Note: Whilst this paper is informed by disabled children, and based on our experience as international child-rights organisation, it does not intend to formally represent disabled children and youth)

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1 Preamble

The draft does not mention children, the committee may want to stress that this convention applies to children as well as adults. We emphasise that children as well as adults with disabilities are entitled to make their own decisions and have their views respected. We recognise children and adults with disabilities as individual rights holders as well as in relation with their social network.

Suggested changes

- c. Reaffirming the universality, indivisibility and interdependence of all human rights and fundamental freedoms and the need for **children and adults** with disabilities to be guaranteed their full enjoyment without discrimination
- g. Recognising diversity **and consequent risks of multiple discrimination** for persons with disabilities
- h. Concerned that, despite the efforts and actions undertaken by Governments, bodies and relevant organisations, **children and adults** with disabilities continue to face barriers in their participation as equal members of society and violations to their human rights in all parts of the world
- k. Recognising the importance for **children and adults** with disabilities of their individual autonomy **and self-reliance**, including the freedom to make their own choices
- m. Concerned about the difficult conditions faced by persons with severe or multiple disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, **age**, sex, language, religion, political or other opinion, national or social origin, property, birth or other status

Suggested additional paragraph

Recognising the importance of social relations and interdependence of children and adults with disabilities at the level of the family, peers and networks beyond in society

Recalling that the CRC emphasises that children, including those with disabilities, are rights holders, entitled to respect for their views in accordance with their age and maturity'.

Draft Article 1 – the purpose of the convention

This article says that the purpose of the convention is to ensure that the human rights of people with disabilities are respected.

Suggested changes

'The purpose of this Convention shall be to ensure the full, effective and equal enjoyment of all human rights and fundamental freedoms by persons, **including children, with disabilities**'.

Draft Article 2 – Principles

This article describes the principles in the convention. We emphasise that all persons with disabilities are rights holders

Suggested changes

- f. **Diversity and equal opportunity of women and men, girls and boys with disabilities**

Draft Article 3 - Definitions

The draft does not provide basic definitions.

Suggested changes

If it is decided to include a definition of 'persons with disabilities; we want to add that this includes children with disabilities.

For example:

'Persons with disabilities' – **applies to children as well as adults, except where national law provides specific legislation excluding all children from particular activities, for example, sexual relations, marriage, employment.**

Suggested additional definition

The text mentions issues of diversity; we therefore recommend a **definition of diversity** as all persons with disabilities are unique. This definition needs to specify disability as an issue of difference, concretise issues of diversity within the community of disabled people. This definition needs to provide a comprehensive view instead of gender, ethnicity in its own and relate diversity with risks of multi-discrimination (on the basis of race, colour, gender, age, communication skills, level of autonomy in daily life, socio-economic status,...)

Draft Article 4 – general obligations

This article sets out the obligations on governments towards persons with disabilities as rights holders. We would wish to ensure active participation of children in developing policies and legislation to implement this convention.

Suggested changes

g. In the development and implementation of policies and legislation to implement this convention, States Parties shall do so in close consultation with, and include the active involvement of, persons with disabilities, **including children**, and their representative organisations.

Draft Article 5 – positive attitudes

This article sets out actions that government must take to challenge discrimination. It says that governments must work with people with disabilities in designing campaigns and programmes.

Suggested changes

We wish to emphasise the intrinsic value and contribution of all children and adults with disabilities, irrespective of their ability to socialise and their level of self-reliance. This we find important to ensure inclusion of severe and multiple disabled persons.

1. c Promote an image of **children and adults** with disabilities as **valuable** and contributing members of society **in their own respect**, sharing the same rights and freedoms as all others and in a manner consistent with the overall purpose of this Convention.

Suggested additional paragraph

1. d **Combat patronising, bullying and neglect on the basis of perceived incapacity of disabled children and adults in public services and society overall**

We wish to ensure that governments must also work with children with disabilities, not just adults.

2.d. working in partnership with persons with disabilities, **including children**, and their representative organisations in all measures taken to give effect to the obligations contained in this article'.

Draft Article 7 – equality and non-discrimination

The text includes 'age' as a ground for non-discrimination. However we wish to ensure a full coverage of the concept of discrimination as currently described in the text.

Suggested changes

We are concerned that the text will allow misunderstanding and inappropriate use. If any distinction needs to be made, this needs to be on the basis of required skills instead of perceived disability. We therefore recommend to remove article:

3 'Discrimination does not include a provision, criterion or practice that is objectively and demonstrably justified by the State Party by a legitimate aim and the means of achieving that aim are reasonable and necessary'

We recognise the need for preparatory or supportive measures in order to, and as long as this is necessary for children and adults with disabilities to address equal rights and to enable full participation. However we wish to emphasise that any such measures need to promote inclusion and prevent segregation of disabled children and adults as such. We therefore recommend a revision of article:

5 'Special measures aimed at accelerating de facto equality of persons with disabilities shall not be considered discrimination as defined in the present Convention, but shall in no way entail as a consequence the maintenance of unequal or separate standards; those measures shall be discontinued when the objectives of equality of opportunity and treatment have been achieved'

Draft Article 8 – right to life

This article applies to everyone including children. However we suggest to add the concept of survival and development. In addition we wish to recognise the rights of all children to be prepared in emergencies.

Suggested changes

In line with the core principles and art 6. of the CRC we propose another title
Draft Article 8 – right to life, **survival and development**

Suggested additional paragraph

8.1 Children and young people have the right to physical, mental, spiritual, moral and social development to the maximum extent possible.

We recognise the global increase in situations of unrest, conflict and disaster, which poses extra risks for children and adults with disabilities upon the chance for survival, security and development.

Suggested additional paragraph

8.2 Children and young people have the right to be prepared, protected and supported in situations of civil unrest, armed conflict, loss of home and habitat, and or their relatives.

Draft Article 9 – equality before the law

This article deals with the right to disabled people to be treated equally in the legal system and to acquire assistance. Where necessary, so that they can enter contracts, sign documents or take care of their own finances. Children, and especially disabled children, are often prevented from taking responsibility for their affairs or to give evidence in court, even when they are capable of doing so.

Suggested changes

9.a States Parties shall recognise persons with disabilities as individuals with rights before the law equal to all other persons; and **respect the rights of children with disabilities to exercise legal capacity in accordance with their evolving capacities.**

9.d States Parties shall ensure that **children and adults** with disabilities who experience **difficulty in communication, accessing and handling information needed to address their rights, can acquire non-partial assistance**, to express their preferences, choices and decisions, as well as to enter into binding agreements or contracts, to sign documents, and act as witnesses

Draft Article 10 - liberty and security

This article does not provide clear arguments or contexts to deprive disabled children and adults of their liberty. Non-voluntary segregation of disabled children and young people from their families is still common practice in various parts of the world. For this reason we recommend a revision of this article to ensure that any segregation and or institutionalisation on the basis of disability and or perceived incapacity as such will be halted. Furthermore the article seems to be primarily based on needs instead of rights and does not become clear who defines the needs: the person him/herself, the authorities or the professional(s).

Some thoughts for change

10.2.

- **Non-voluntary deprivation of liberty only might be considered and or enforced if the person is causing serious danger to himself or his/her environment**
- **Deprivation of liberty voluntarily can be considered if this prepares or supports the person back to his/her own household, daily life and participation in education, job, household or leisure. Another reason can be to provide the necessary temporary respite to the carers**
- **Deprivation of liberty needs to be focussed on reintegration rather than long term or permanent separation**

Draft Article 11 – freedom from cruel, inhuman and degrading treatment

This section covers very different issues, deserves more coherence with art 10 &12 and thus requires fundamental change.

Some thoughts for change

11.1 This article does not seem to cover the increase in threatening and inflicting cruel acts aimed to maim and traumatise children and adults in situations of upheaval, conflict and war. This is especially true in the context of recruiting child-soldiers and

street-gangs; but also where disabled children are separated from their family or live in institutions.

11.2 see comments for article 10

Draft Article 12 - freedom from violence and abuse

This article is important for children. Children generally are extremely vulnerable to violence and abuse. And in most countries in the world, it remains lawful to hit them. Disabled children are even more vulnerable. So, it is important to emphasize that children with disabilities must have the same level of protection as adults with disabilities. Many children and young people with disabilities have also argued the importance of sensitizing parents to understand their children's rights not to be hurt and abused.

Suggested changes

12.1 States Parties recognise that persons with disabilities, **in particular women and children**, are at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual exploitation and abuse. States Parties shall, therefore, take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual exploitation and abuse. **These measures shall acknowledge the equal rights of children to protection from all forms of violence and abuse.**

Suggested additional paragraph

12.2. States Parties shall take all appropriate measures to establish child protection mechanisms which are accessible to children with disabilities, including information on accessing help, training of all relevant professionals, introduction of child protection policies in all institutions, parent education programmes, and safe reporting procedures.

Draft Article 13 – freedom of expression and access to information

Children with disabilities are often denied access to information and therefore the right to express themselves. Bullying and neglect is a problem expressed by many disabled young people. It is important that governments provide information for children and adults with disabilities.

Suggested changes

States Parties shall take appropriate measures to ensure that persons with disabilities can exercise their right to freedom of expression and opinion through Braille, sign language, and other modes of communication of their choice, and to seek, receive and impart information, on an equal footing with others, including by:

13.a providing public information to **persons** with disabilities, **including providing age-appropriate information for children with disabilities**, on request, in a timely manner and without additional cost, in accessible formats and technologies of their choice, taking into account different kinds of disability

suggested additional paragraph

13.b enabling children and adults to communicate on an equal footing with others by providing extra time to access, reflect and act upon information, by providing plain information and facilitating augmentative and alternative modes of communication

13.c enabling children and adults to appoint a representative if alternative modes of communications don't suffice to express and participate on an equal footing

Draft Article 14 – respect for privacy, the home and family

This article deals with the rights of people with disabilities to privacy and to family life. We wonder if the title covers the content of this article. One of the issues children and youth with disabilities prioritize is the assumption that parents and caretakers are their spokespersons. Children and young people want parents and caretakers to respect their ability to make their own decisions and begin to be more independent as they grow up.

Additionally we emphasize the need for a coherent prohibition in the convention text to remove children from their homes against the will of parents and or the child, only on the basis of perceived incapacity due to disability.

Suggested changes

Title article 14 – respect for identity, the home and family

14.2 States Parties to this Convention shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage and family relations, and in particular shall ensure:

14.2a 'the rights of children with disabilities to respect for increasing levels of autonomy within the family in accordance with their evolving capacities';

Draft article 15 – living independently

This article deals with the right to autonomy and inclusion. However we recommend an emphasis on the right to be self-reliant as well as the right to play a constructive role in society at all levels so as to enable participation to the fullest. The concept of independent living as such is not aimed for in many countries and particularly not for children and youth with disabilities. This article needs to embed the concept of family and peers wherein children and adults with disabilities participate.

Last but not least we emphasise the right to live in the community and importance of support services which make this possible.

Suggested changes

States Parties to this Convention shall take effective and appropriate measures to enable **children and adults** with disabilities to **become self-reliant** and be fully included in the community, including by ensuring that:

15.c that persons with disabilities have access to **home based, community based** support services necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.

Draft article 16 - children with disabilities

The current text is mainly taken from Article 23 of the Convention on the Rights of the Child. There, it is an article focusing on disability in a convention for children. But here, it needs to address a comprehensive child-perspective in this Convention. We object that basic services are made subject to available resources. We emphasise the need for inclusive basic services as a rule and special services as an exception. We wish to focus on the rights and abilities of disabled children rather than to label disabled children upon their needs and problems.

Suggested changes

- 1 States Parties undertake to comply with their obligations to children and young people with disabilities under the Convention on the Rights of the Child.**
- 2 States Parties recognise the obligation to respect the evolving capacities¹ of children with disabilities in the exercise of their rights, and the right to express their views freely on all matters affecting them, their views being given due weight in accordance with the age and maturity of the child². To ensure that children with disabilities enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and autonomy and facilitate the child's active participation in the community.**

Suggested additional paragraph

- 3 States respect the obligation to include disabled children and youth in basic services for all. States develop special services only for those disabled children who require preparation for inclusive services and to support basic service structures to be inclusive for all children covering all aspects of child life³.**

Suggested change

- 3->4** States Parties recognise the right of children with disabilities to inclusive care, **within their community, relevant for their daily life**, which shall include:
 - (a) early provision of appropriate and comprehensive services;**
 - (b) advisory & facilitative services to enable disabled children to participate in basic services and to support the basic service infrastructure to be truly inclusive**
 - (c) assistive services for the child and his/her caretakers to prepare, support the full development and inclusion of the child in all aspects of child life and child rearing.**
- 4->5** Recognising the **rights and abilities** of children with disabilities, assistance extended in accordance with paragraph 3 of the present article shall be provided free of charge, **or a sliding scale** taking into account the financial resources of the parents or others caring for the child;
- 5->6** Children with disabilities and their parents or other persons caring for or legally responsible for the child shall be provided with appropriate information, referrals and counselling, and information made available in these ways should provide them with a positive view of their potential and right to live a full and inclusive life.

¹ This concept relates to art 5, 6, 23 and 29 of the CRC

² This paragraph is related to art 12 of the CRC posing clear obligations on governments to ensure that children and young people are not passive recipients of adult protection, but that they have the right to have a say in all actions and decisions affecting them, from the family to the wider community level. However to date, too little action has been taken by governments around the world to ensure that the right to be heard extends to disabled children. (Lansdown G. 2001 'Its Our World Too! A report on the Lives of Disabled Children for the UN General Assembly Special Session on Children, Disability Awareness in Action, London)

³ Between 2000-2000, Rights for Disabled Children, an international working group of disabled people's organisations undertook analysis of each government report due to be examined by the Committee on the Rights of the Child. It was found that although governments did seek to address the issue of children's participation, albeit inconsistently, they rarely, if ever, mentioned participation with regard to disabled children.

7 States Parties shall recognise the particular vulnerability of children with disabilities to abandonment and rejection, and take all appropriate measures to provide assistance and education to parents in the performance of their child-rearing responsibilities in order to minimize the likelihood of rejection. Where children with disabilities are unable to live with their parents, every effort shall be made to provide alternative family care, the best interests of the child being the paramount consideration in such placements.

Draft Article 17 - education

The basic principle is that disabled children and adults, like all persons have a right to education. We emphasise the obligation of governments to provide compulsory and quality education for all children and adults. We emphasise the importance of equal access, utility of education and child-focussed methods enabling disabled children, like all children to achieve their full potential. We wish to avoid pre-selected training or any kind of education on the basis of perceived disability instead of the potential of the child.

Suggested changes

17.4 States Parties shall ensure that children with **communication**⁴ disabilities may choose to be taught in alternative language and to receive a curriculum in this language. States Parties shall take appropriate measures to ensure quality education to students with **communication** disabilities by **ensuring skilled teachers and basic additional resources**

Draft Article 18 - participation in political and public life

This section is written to ensure that people with disabilities are allowed to vote, stand for election and take part in public affairs. The Convention on the Rights of the Child says that children have a right to be heard on issues that affect them. This includes legislation and policies. Many governments have begun to set up consultation forums for children and young people, but very often children with disabilities are excluded. We therefore want to include a section, pointing out that children have the right to be involved.

Suggested changes

States Parties recognise the political rights of persons with disabilities, without discrimination, and undertake to:

18.b actively promote an environment in which persons with disabilities, **including children**, can effectively and fully participate in the conduct of public administration, and shall encourage, as appropriate, their participation in public affairs, including to:

(c) to ensure that persons with disabilities, **including children**, and their organisations participate, on an equal basis to others, in all decision-making processes, in particular those concerning issues relating to persons with disabilities.

Draft Article 19 - accessibility

⁴ communication disabilities does not only refer to those persons who are blind or deaf, but also to those persons who have a major problem to contact others, to express themselves, to filter and handle information for various reasons (eg. People with autism, severe spasticity, learning and intellectual impairments)

This is a high priority for young disabled persons. The article does cover most of the issues and also requires governments to consult with disabled people. However, to often, children get left out of those processes.

Suggested changes

19.2 States Parties shall also take appropriate measures to:

g. 'ensure organisations of persons, **including children**, with disabilities are consulted when standards and guidelines for accessibility are being developed';

Draft Article 20 – mobility

The perception of mobility appears to be limited in this article. Mobility is crucial for all persons including disabled children to be active and participate in all aspects of life. Mobility is more than freedom of physical movement as such and needs to embrace daily life skills⁵ and communication, to mention a few aspects of life.

The concept of universal design seems to be quite western dominated and we would advise to consider diversity in geographic / economic context as well as in life stages. We wish to emphasise the access to technology with high quality standards, effective maintenance facilities and against affordable costs for a large group of persons.

Draft Article 21 – health (and rehabilitation)

The coverage of both health and rehabilitation in one article is questionable as it just perceives rehabilitation as a component of health. We suggest to draft an article on health and a separate article on rehabilitation. With regard to health we advise to follow a similar pattern as in the education article. Aiming for accessible & quality health services for all, including disabled children and adults, as the rule and specific services as an exception to prepare for and support basic health services. The entire article on health needs to be revised into a less medical-technical language.

Suggested change

States Parties recognise that all persons with disabilities have **full access** to health services and the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. In particular States Parties shall:

- a. provide persons with disabilities with the same range and standard of health services as other citizens, including sexual and reproductive health services
- b. develop understanding of disability rights, respect for diversity, non-discriminatory attitudes and a realistic perception of the capacities of disabled people as users of health services for health professionals at all levels, in line with the principles of this Convention
- c. involve children and adults with disabilities and their respective organisations in the development and monitoring of health policies and of a code of ethics for public and private health care, promoting quality, transparency and respect for human rights at national level
- d. strive to provide specific health services needed by persons with disabilities to **enable optimal development potential and self-reliance in daily life**
- e. ensure that respect is afforded to children and adults with disabilities to give consent to or refuse medical interventions of all kind, in accordance with their evolving capacities. Arrange decision-making in accordance with earlier articles in this convention⁶

⁵ eg child-rearing, running a household, personal hygiene, recreation, accessing education, employment, etc

⁶ in relation to our comments with regard to article 9, 10, 13 of this draft convention

Draft Article 21a – rehabilitation

The access to basic rehabilitation is particularly important for disabled children and all persons with recently acquired, chronic or progressive disabilities. We advise that the recommendations of the International Consultation to review CBR⁷ will be furthered in the final wording of this article

Suggested change

States Parties shall take all appropriate measures to ensure access, quality and utility of rehabilitation services. In particular, States Parties shall:

- a. facilitate the development of comprehensive rehabilitation strategies, resources and services starting in the community and supported by secondary and tertiary services, including the provision of respite places
- b. develop rehabilitation strategies with disabled children and adults which enable full development, prevention of secondary disabilities, self-reliance in daily life, participation in all aspects of life and society
- c. promote co-ordination of rehabilitation services with basic services in the daily life environment of children and adults with disabilities preparing full participation in, and the development of inclusive services
- d. ensure full participation of representative organisations of disabled children and adults in the development of policies, strategies and programs in rehabilitation ensuring these services to be responsive to the actual needs of disabled persons
- e. facilitate the mobilisation of democratic and representative of self-help groups, disabled people organisations from the local to the national level, representing diversity and countering discrimination among disabled people
- f. encourage research, dissemination and application of new knowledge that will benefit persons with disabilities

Draft article 22 – employment

No major objections from a child perspective

Draft article 23 – social security

No major objections from a child perspective

Draft article 24 - Participation in cultural life, recreation, leisure and sport

Participation in sport, recreation and leisure is a priority for many disabled children and young people. We recommend a paragraph how the right to play and recreation can be met.

Suggested changes

States Parties recognise the right of all persons with disabilities to take part in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:

⁷ WHO (2003) Report of International Consultation to Review Community Based Rehabilitation, Helsinki, Finland
www.who.int/ncd/disability

24.b. enjoy access to literature and other cultural materials in all accessible formats, including in electronic text, sign language and Braille, and in audio and multi-media formats, **and that such access also extends to literature and cultural materials appropriate for children with disabilities;**

Suggested additional paragraph

24.4 States Parties recognise the right of persons with disabilities, on an equal basis with others, to participate in recreational, leisure and sporting activities, and shall take appropriate measures to:

24.4.a. ensure that children with disabilities have access to age appropriate play and recreational facilities.

Draft article 25 – monitoring

No major objections from a child perspective