



EDF position paper

on the draft International Convention text resulting from the Working Group meeting in January 2004 in New York

INTRODUCTION

The European Disability Forum (EDF) has been taking part in the process leading to the UN Convention to protect and promote the rights and dignity of persons with disabilities from the very beginning. EDF has obtained consultative status during the first Ad Hoc Committee meeting in 2002, has attended the Ad Hoc Committee meeting in 2003 and was represented by its President Yannis Vardakastanis, who was one of the twelve DPO representatives, at the Working Group which met in January 2004 in New York.

EDF has been co-operating in this process with the other international DPOs active in this process. A special moment of this co-operation was the meeting hosted by EDF, with the support of its associate member Fundacion ONCE, in Madrid in December 2003. The twelve DPO representatives in the Working Group, as well as other experts from the disability movement, attended this meeting.

EDF has maintained its wide membership informed about this process. A meeting was held in April 2003 in Spain which was devoted to finalising an EDF contribution prior to the Ad Hoc Committee meeting in June 2003.

EDF and its members have also been actively campaigning towards the EU (including the accession countries) to ensure a positive attitude of the European Union in this process. Seven of the 15 EU Member States included in 2003 representatives from the disability movement in their delegations. We expect that this presence in national delegations will be maintained and even increased in forthcoming meetings.

The present contribution has been prepared following a thorough consultation with EDF's member organisations.

There are some general issues which we would like to address initially before making comments to the specific articles of the draft Convention which resulted from the meeting of the working group held in January 2004.



GENERAL COMMENTS

Title

The title of the future Convention could be International Convention on the Rights of Persons with Disabilities (CRPD).

Families

The UN Convention is to protect the rights of persons with disabilities as individuals.

However, it is obvious that the family of children and of adults with disabilities who can't represent themselves plays a key role in the process to ensure the protection and promotion of the rights of persons with disabilities.

A well supported, well informed family will be an important ally to ensure the protection and promotion of the rights of persons with disabilities. On the contrary, an ill-informed family can be a serious obstacle to the full enjoyment of the human rights of persons with disabilities.

Over protection, prejudice, low expectations and shame are often elements to be found among badly informed families.

This is why the UN Convention cannot ignore the role of the family; it has to take into account the role of the family from the point of view of the disabled person.

The UN Convention needs to include measures that will ensure that the family of a disabled child or adult contributes to the full enjoyment of the human rights of persons with disabilities, but maintaining always the focus on the target group of the Convention; that is, the persons with disabilities.

This is why EDF proposes to include specific references to families in the following articles:

- Promotion of positive attitudes to persons with disabilities (draft article 5). Campaigns need to be addressing families of disabled people.
- Right to health and rehabilitation (draft article 21). Parents of disabled children need to be given early and correct information on the impairment of their child to ensure an adequate health and habilitation treatment.
- Social security and an adequate standard of living (article 23). The extra costs related to disabled children and adults unable to represent themselves have to be covered by the State and not by the family. Special attention needs to be given to the situation of people with complex dependency needs.



- Freedom from violence and abuse (draft article 12). Special measures need to be taken to protect disabled people from violence and abuse within their family environment.
- Education (draft article 17). Parents of disabled children need to be given the correct information to make the best choice for their child.

International cooperation

EDF considers that international cooperation can never be used as an excuse for inaction by developing countries.

However, EDF also considers it unacceptable that development cooperation funds will continue to ignore the human rights of disabled people. In other words, disabled people must be fully included in all aspects of international co-operation and international funding agreements. They have to be considered a target group of international cooperation.

EDF supports the obligation of all States to mainstream disability in all policy areas as a General State Obligation, as stated in draft article 4.

This obligation should also include the provision of development cooperation funds (donor countries) as well as the use of development cooperation funds (recipient country). EDF therefore proposes to make a reference to this in the draft article 4 on General State Obligations. It is also proposed to include a reference to international cooperation in the preamble, like in the Convention on the Rights of the Child (CRC).

Involvement of disability organisations in policy making

This has to be considered as a cross-cutting element throughout the Convention. It has to be included in the General State Obligations and mentioned again in the most relevant articles.

However, consultation is not enough. The participation of the representative disability organisations has to be meaningful and has to include all stages of any policy or legal initiative: the design, the implementation, the monitoring and the evaluation.

When EDF refers to representative organisations of disabled people, this concept has to include not only organisations of disabled people, but also organisations of parents of disabled people unable to represent themselves. This has to be made clear in the text of the Convention.

The involvement of disability organisations has to be referred to as an obligation in the implementation and monitoring of the Convention, but is of course not restricted to this.



It is also proposed to include a specific section on the freedom of association in the draft article dealing with participation in political and public life (draft article 18).

Progressive realisation

It is obvious that many of the measures which States will need to undertake in order to ensure the effective and equal enjoyment of all human rights by disabled people require financial resources and will also require time for their full implementation. The level of economic development of the different countries will also influence this process.

On the other hand, there are many measures that require no or little financial resources. For these measures, the principle of progressive realisation should not be applied.

A same right might require measures which can immediately be applied and measures which need to be applied progressively.

An example is the right to vote: the elimination of laws which prevent some disabled people from voting can and has to be applied immediately, but the obligation to make polling stations accessible, may require financial resources and therefore might not be done immediately.

The right to accessibility is another example. Obviously, to eliminate the current barriers immediately is beyond the financial resources of all countries, but preventing the establishment of new barriers is possible for even the least developed country.

When measures are to be applied progressively, there has to be an obligation on States to establish, in consultation with representative disability organisations, a reasonable timeframe for the implementation of these measures and States will be obliged to respect this timeframe. This has to be specified in the monitoring and implementation section of the Convention.

SPECIFIC COMMENTS

Preamble

A reference to international cooperation should be added, in line with what is mentioned in the previous section.



The preamble should include a paragraph which reminds that this Convention covers girls and boys with disabilities, young women and men with disabilities, adult women and men with disabilities, as well as older women and men with disabilities.

Paragraph p) should also include terrorism and natural disasters.

Paragraph m) should be reworded to make clear that the groups referred in this paragraph have additional problems to other disabled people and therefore require even more attention. The listing should also include disabled people from indigenous minorities, as well as those living in rural and remote areas.

Draft Article 1 Purpose

The objective should state: *“The purpose of this Convention shall be to ensure **and promote** the full, effective and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities”.*

Draft Article 2 General Principles

Whichever word is finally used (individual autonomy or self-determination) it has to be made clear that its meaning includes the right to make one’s own choices and decisions, which is a key principle.

EDF proposes to add the principle of effective and substantial equality as a guiding principle, which is stronger than equality of opportunity.

Draft Article 3 Definitions

If a definition on disability is to be included, it has to reflect the social model and it has to be broad, not leaving any group of disabled persons out. For instance, the use of the ICF definition would imply the risk of leaving certain groups of disabled people out.

The Council of Europe has agreed on a definition of Universal Design, which might be considered useful for the Convention. The definition reads : *“Universal design is a strategy, which aims to make the design and composition of different environments and products accessible and understandable to, as well, as usable by, everyone, to the greatest extent in the most independent and natural manner possible, without the need for adaptation or specialised design solutions.”*

Draft Article 4 General Obligations

The initial paragraph should state, as in the ICCPR, that States “shall **respect** and ensure the full realisation of all human rights and fundamental freedoms.”



Paragraph a) should also include by-laws, rules and we suggest to replace the word “discourage customs” by “counter customs”.

EDF proposes to add to paragraph c) a reference to international cooperation, which would oblige both the donor and the recipient of development cooperation funds to take into account persons with disabilities.

EDF also considers it very important that a paragraph on remedies is included in this article.

EDF also suggests to add a reference to positive action measures to paragraph e) of this article.

EDF suggests a reference to the use of public procurement and public funds in paragraph f) as a way of promoting Universal Design in goods, services, equipment and facilities.

When implementing the General State Obligations, special attention should be given to those disabled people more in danger of exclusion and discrimination, including women with disabilities, disabled people from ethnic minorities, disabled people living in rural and remote areas.

Paragraph 2 of this article is considered of vital importance. It could be strengthened through a reference to the concept of partnership and to the provision of measures which would strengthen the role and capacity of representative organisations of persons with disabilities to play an active role in the implementation of the Convention.

Draft Article 5 Promotion of positive attitudes to persons with disabilities

The change in attitudes and the combating of mental and attitudinal barriers is a key element to contribute to the human rights of disabled people. As such, it is a cross-cutting issue which affects all areas of life. It might be considered to move this article to a different part of the Convention, in a section on supporting measures.

EDF proposes to add a specific paragraph on measures addressed to families of children with disabilities.

Finally, some reflection should be given to the wording “positive attitudes”, as this might continue to lead to stereotyping. Awareness raising measures on the rights of persons with disabilities might be a more appropriate phrasing.



Draft Article 6 Statistics and data collection

The collection of statistics, if done properly, might contribute to the design of policies and legislation which promote and protect the rights of persons with disabilities.

EDF suggests to link this article to the article on national monitoring.

Draft Article 7 Equality and non-discrimination

EDF suggests to include a specific reference to effective equality in this article, which is to be obtained through a combination of non-discrimination and positive action measures.

EDF welcomes that the article clearly states that disabled people should be protected from all forms of discrimination and welcomes a specific reference to direct, indirect and systemic discrimination. The recognition of the reversal of the burden of proof acknowledged in recent EU legislation should be included in this article.

EDF supports the inclusion of the provision stating that the failure to provide a reasonable accommodation is to be considered as discrimination, as also reflected in General Comment 5 of the ICESCR. If a reference to disproportionate burden is to be maintained, this needs to be qualified taking into account different elements like: the size of the organisation, the existence or not of financial incentives to compensate partly or totally these costs.

The exception clause included in paragraph 3 causes great concern to EDF. It should be deleted.

EDF strongly supports the idea reflected in paragraph 5. The Madrid Declaration adopted in 2002 clearly referred to the fact that a combination of non discrimination and positive action measures are needed to obtain the final objective of full participation of disabled people. We suggest to replace the word “special measures” by “positive action measures”. It should be stated that these measures should not be imposed against the will of the disabled person.

The article should also include a specific reference to multiple discrimination. The reference to the other forms of discrimination in paragraph 1 attempts to do this, but is not clear enough.

The Convention should also protect persons who are perceived (by others) to have a disability and who have had a disability in the past.



Draft Article 8 Right to life

The wording in the Convention on the Rights of the Child is stronger and could be used for this Convention: *“States Parties shall ensure to the maximum extent possible the survival and development of the disabled person.”*

There are different views among EDF members on whether this Convention can cover or not the rights of a non-born disabled child. If the Ad Hoc Committee finally decides that this is possible, a prohibition of compulsory abortion at the instance of the State based on the pre-natal diagnosis of disability should be added to this article.

Draft Article 9 Equal Recognition as a person before the law

EDF supports the way in which this article is drafted. The focus of this article has to be on assisting disabled people, who so need, to exercise their legal capacity. This article should have as a consequence the abolition of all old-fashioned and wrongly conceived guardianship laws.

EDF agrees with the concerns raised in the footnotes corresponding to this article, in particular regarding the need to protect persons with disabilities who cannot exercise their legal capacity.

EDF supports to keep paragraph (d) in this article.

Draft Article 10 Liberty and security of the person

EDF considers very important that no deprivation of the liberty of a person is made on the ground of disability.

Paragraph 2 of article 10 is weaker than existing rights under international law. It therefore should either be deleted or changed accordingly. Indent d) of this paragraph should be kept.

Draft Article 11 Freedom from torture or cruel, inhuman or degrading treatment or punishment

EDF strongly supports the prohibition of forced interventions and forced institutionalisation in this article as well as in draft article 12.

Draft Article 12 Freedom from violence and abuse

A special reference to disabled women and girls should be added in the first paragraph.



EDF proposes to add a specific paragraph which will protect disabled people from violence and abuse within their family environment.

Also important, is to include a reference to statistics on violence against disabled people, including disabled women and girls.

A specific paragraph on abuse that disabled people suffer from private individuals should also be included. Hate crime, manifested either verbally, physically or both, harassment and other forms of violence and abuse should be referred to and the measures to prevent this from happening should include legal remedies.

EDF also supports the inclusion of a specific reference to legal remedies in paragraph 6 of the article, as suggested in footnote 39. This should include penalties for those found guilty of violence against disabled people.

Draft Article 13 Freedom of expression and opinion, and access to information

If a definition of the modes of communication is given in article 3 (Definitions), there would be no need to restate the different modes of communication in the initial paragraph of this article.

The recognition of sign language as the natural language of many deaf persons would require a specific paragraph, as there are many reported situations in which deaf adults and children have been prevented from using sign language.

Paragraph a) should require that public authorities make their websites accessible to disabled people. This will not be upon request, but from the outset.

Paragraph e) of this article should include the examples given in footnote 43.

Paragraph f). When these private entities obtain public contracts or public funding, the provision of information in an accessible way has to be a compulsory condition.

Draft Article 14 Respect for privacy, the home and the family

EDF supports the use of the word “communication” instead of correspondence in paragraph 1 of this article.

Also, paragraph 1 should cover other relations, apart from marriage and family.

EDF supports a specific reference to prohibition of sterilisation on the ground of disability in this article.



The wording of the second sentence of paragraph e) needs some reflection and justification. The objective is that a child is not taken away from her/his parents because their parents have a disability. In principle, the first paragraph covers this, but we fear that often misconception, prejudice and low expectations against disabled people will influence the decision. The proposed wording seems therefore an important additional protection.

EDF supports the proposal, mentioned in the footnote, to include the following sentence: “State Parties shall render appropriate assistance to parents with disabilities to enable their children to live with them.”

Draft Article 15 Living independently and being included in the community

EDF supports the reference to living independently. This makes clear that disabled people have the right, as all other citizens, to choose the way in which they want to live, choice which will include to live with their family or not.

The situation of so many disabled persons confined and secluded against their will in large residential institutions is one of the key issues this Convention should solve. It is therefore very important to maintain paragraph b) of this article.

For those disabled people that freely choose to live in an institution, provisions need to be set in place to ensure that they have full saying in the way their institution is managed, as well as specific protection of their rights.

Draft Article 16 Children with disabilities

EDF proposes to limit the reference “subject to available resources” in paragraph 3b.

EDF supports the paragraphs referring to the support to be provided to the families as a key element for promoting the rights of disabled children.

The article might include a paragraph which protects the disabled child from possible negative situations within the family. This should be based on a reference to the best interests of the child, in line with the content of the Convention on the Rights of the Child (CRC).

Draft Article 17 Education

This is one of the most important and complex areas. Therefore, before making concrete comments to the draft article, some general comments might be useful on the objectives to be achieved with this article.



First and foremost, the right to education for all disabled children, youngsters and adults has to be recognised and this education has to be of the same quality as that of their non disabled peers.

The most complex is the issue of mainstream and special education. Special education can be provided in special schools, but also in special classes within mainstream schools.

The decision between special and mainstream education is an issue for which the level of economic development of countries needs to be taken into account.

In an economically developed country, the existence of special schools is difficult to justify. An exception to this general rule is the education of deaf children who use sign language as their first language. The organisations of the deaf defend the special schools as the preferred option. All other groups consider mainstream education as the preferred option.

Nevertheless, inclusion in mainstream schools can only be the best option if the adequate support is provided to the disabled child. As long as this support is not provided, special schools need to continue to exist to ensure the right for a quality education.

However, the general objective to be promoted is the integration in mainstream education.

Finally, meaningful choice is a key issue for the child and for the family, which plays a decisive role in the decision on which education type to choose. A reference to the key role of the parents in choosing the education of their disabled children, needs to be included.

The article has to cover more clearly all stages of education and cover all persons with disabilities. Therefore the reference in the initial section of paragraph 1 should refer to persons with disabilities and not only to children with disabilities. The same applies to paragraph 1 c). In order to avoid confusion, we suggest always to refer to education and not to learning.

EDF considers that the structure of the article is not very clear. In our view, the first paragraph should deal with the right to education and the right to the same quality education as the non-disabled peers. We suggest therefore that the paragraph 2c) is moved to paragraph 1.

Paragraph 2 should refer to the mainstream education system and paragraph 3 to special education.

EDF supports in paragraph 2b) the inclusion of a reference both to the need to have specialised support teachers as well as a general disability awareness



training among all education professionals. A special reference to information and communication technologies should also be included in this paragraph.

Paragraph 3d should say “continue to realise the needs of students with disabilities”.

Paragraph 4 should better read “proficient in braille” instead of “fluent in braille” which seems to imply that braille is a language. This paragraph applies both to mainstream education and to special education.

Paragraph 5 of the article should include a non exhaustive list of assistance to be provided to persons with disabilities to ensure their participation in tertiary education and vocational training.

Draft Article 18 Participation in political and public life

The right to vote, by secret ballot, and to stand for elections has to be explicitly guaranteed. The article has to make clear that it covers persons with all types of communication disabilities.

The article should also refer to accessible information and election materials and ensure the full participation of disabled people in all stages of the electoral process.

This article should refer specifically to the freedom of association of disabled people. EDF supports the proposed article (23.2) included in the Bangkok draft, which states that :

“(a) All persons with disabilities have the right to freedom of association.

(b) States Parties shall take all necessary measures to:

- (i) recognize the right of persons with disabilities, their family members and supporters to form independent organisations for representation and self help; and*
- (ii) provide recognition and financial support to such associations in order to promote the full realization of the rights of persons with disabilities.”*

Draft Article 19 Accessibility

EDF supports a stronger prohibition of barriers to all new buildings and other transport or communication premises. For currently existing barriers, a timeframe for their elimination should be established.

Paragraph b) should include also auditory signals.

Paragraph d) should include a reference to public procurement and public funds. This would mean that when an entity receives public funds or opts for a public contract, the entity needs to provide its services in an accessible way.



Some coherence is required between article 19 and article 20 on personal mobility. Article 19 should be focused on the conditions a building or other infrastructure should meet to ensure that it is accessible to all disabled people. Article 20 would focus on measures to ensure that a disabled person can freely move from one place to another.

This would mean for instance that sign language interpreters when they are available in the public building would be included in article 19, but if they accompany the disabled person to different places, it would be covered by article 20.

There are references to assistive technologies in paragraphs e) and f) which seem to be more suitable for the article 20 on personal mobility.

Draft Article 20 Personal mobility

Training referred to in paragraph d) should also cover other persons associated with rehabilitation and support work with people with disabilities.

If a disabled person needs to be accompanied by a personal assistant in using public transport, the personal assistant should travel free of charge. This should be specified in paragraph e)

Draft Article 21 Right to health and rehabilitation

This article might be clearer if it is divided into two articles: one dealing with the access of disabled people to general healthcare issues and a second one dealing with the specific (re)habilitation issues which some disabled people require.

As referred to in footnote 74 of the draft Convention, (re)habilitation goes beyond medical issues. A definition of both concepts (rehabilitation and habilitation) in the article 3 seems to be appropriate.

EDF is against a reference to prevention of impairments, but supports a reference to the prevention of secondary impairments as included in paragraph e).

Draft Article 22 Right to work

This article should include a clear prohibition of all forms of discrimination, including harassment, against disabled people in the workplace, covering all parts of the process: recruitment, career advancement, life-long learning, dismissal.



The failure to provide reasonable accommodation has to be considered as a form of discrimination. A non exhaustive list of reasonable accommodations should be given, including workplace adaptations, change in working time patterns, reallocation of non essential tasks, personal assistants.

Paragraph b) could be strengthened by a requirement that when these services are publicly financed, they have to be accessible to disabled people.

Paragraph (g) when it refers to job retention should state “job retention at the onset of a disability”.

Paragraph h) should include specifically hiring in the areas to be covered.

An additional paragraph should be added to protect disabled people from being required to provide to their employer non relevant health information.

When a disabled person requires rehabilitation, the disabled person should be given the required time to do this.

Another element which should be included is how to ensure that health and safety measures are applied in a non discriminatory way to disabled persons.

Disabled people work both in the open labour market as well as in other forms of more special employment arrangements, like sheltered/supported workshops and social enterprises. The Convention has to protect the rights of disabled people in all employment situations and in particular in these special settings, where disabled people are at a higher risk of being exploited.

Finally, to make the right to work a reality for all disabled people in working age, different employment options need to be provided to disabled people, including a sufficiently broad range and quantity of supported employment opportunities, with varying degrees of support as required.

It should be stated that all these obligations refer both to private and public employers. Current paragraph i) should be reworded, as it seems to imply that equal opportunity to employment of persons with disabilities only applies to the public sector.

Draft Article 23 Social security and an adequate standard of living

EDF considers that paragraph c) should cover all disabled people who are faced with extra costs linked to their disability. At the same time, EDF supports a specific reference, as foreseen in the current draft, to persons with severe and multiple disabilities as a group for which this right is particularly relevant.



EDF proposes to rephrase subparagraph 1e) which in its current wording reminds of old times when disability was approached from a charitable point of view. EDF proposes therefore to indicate that tax benefits or exemptions will be used as one of the ways to compensate disabled people from their disability-related expenses.

The overall objective to ensure is that disabled people obtain their equal share in the economic development of their country.

A specific reference to the obligation to include persons with disabilities in the national poverty reduction strategies should also be added.

The article might be split up into two articles, one dealing with social security and another dealing with adequate standard of living.

Draft Article 24 Participation in cultural life, recreation, leisure and sport

EDF proposes to reword paragraph 1 a of this article as follows: "enjoy access to artistic and cultural practice and benefit of all necessary human and technical assistance and adapted services, to have the opportunity to develop and utilise their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of their community."

EDF also proposes to add a reference to audio description to paragraph 1 c.

While the priority should be put on the possibility for disabled people to access and take part in mainstream sport, support should also be provided for special sport activities.

EDF supports the reference made in paragraph (3) and suggests to refer to "persons who are deaf and use sign language". As mentioned when referring to article 14, not all deaf people are sign language users.

Draft Article 25 Monitoring

EDF considers that the Convention needs to include strong monitoring mechanisms, both at national as well as at international level. The UN Standard Rules and its proposed supplement could be taken into account in the national implementation and monitoring framework.

To ensure that the rights included in the Convention become a reality, disabled people and their organisations need to have easy access to instruments at national level which they can use to enforce the implementation of the Convention.



Special attention needs to be given to the monitoring of these obligations which will be subject to progressive realisation. As stated previously, there has to be an obligation on States to establish, in consultation with representative disability organisations, a reasonable timeframe for the implementation of these measures and States will be obliged to respect this timeframe.

The role of the representative organisations of disabled people is vital in this process and they must be integral part in any implementation and monitoring framework to be established.

EDF strongly supports the different actions such an implementation and monitoring framework should undertake, as highlighted in footnote 114, namely:

- promoting awareness of the provisions of the Convention to persons with disabilities and to the general population;
- monitoring national legislation, policies and programmes to ensure consistency with the Convention;
- undertaking or facilitating research on the impact of the Convention or of national legislation;
- developing a system for assessing that impact on persons with disabilities; and
- hearing complaints about failure to observe the Convention.

A new paragraph should be added which obliges the State to undertake a nationwide information campaign on the content of this Convention, with specific attention to the different key target groups (employers, education providers, healthcare providers, etc..).

New article on international monitoring

EDF is aware of the current process within the United Nations to review the way the existing international Conventions are being monitored.

EDF strongly believes that the forthcoming Convention should in no way have lower provisions than the current Conventions.

This would include the establishment of a Committee, composed by a majority of disabled people (including the Chair) from both developed and developing countries, equal participation of women and men and representing the different impairment groups. The Committee would receive periodic national reports, be able to initiate inquiry procedures, as well as receive individual and group communications.

The participation of the representative international organisations of disabled people in this process also needs to be ensured.

Brussels, April 2004