

After discussions with many delegations and NGO representatives the Facilitator on Article 7 would like to make the following proposal to move forward on **Article 7 para. 5**:

~~[Positive] Measures aimed at accelerating de facto equality of persons with disabilities shall not be considered discrimination on the basis of disability. 7 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.~~

Explanation:

Delegations have expressed differing views on the second part of the current draft and have expressed concerns mainly with respect to two issues:

- 1.) **Temporary measures:** The previous draft included a sentence taken from Art. 4 (1) CEDAW (cf. below), which stipulates that temporary measures to accelerate de facto equality must be discontinued when the objectives have been achieved. The measures looked at in the context of disability are, however, better comparable to those outlined in Art 4 (2) CEDAW, relating to maternity. It follows that it is not necessary to specify in this Convention when measures should be discontinued. In addition, the opening phrase clearly states that only “measures aimed at accelerating *de facto* equality of persons with disabilities” are covered by this paragraph, which would thus not apply to “outdated” measures, since they can no longer accelerate equality.
- 2.) **Unequal or separate standards:** Discussions have revealed great differences in the interpretation of “unequal or separate standards”, which was interpreted by some as restricting too much States’ ability to adopt certain desirable measures, in particular for groups of persons with disabilities with very specific needs. Other delegations were concerned that the deletion of this phrase would allow States to adopt measures whose consequences could amount to segregation (e.g. in schools). Once again, a comparison with Art. 4 (2) CEDAW seems appropriate, which does not mention “unequal or separate standards”. The concern that States might adopt measures which lead to segregation should be covered on the one hand by the opening phrase “measures aimed at accelerating *de facto* equality of persons with disabilities”, as well as by the many substantial standards established throughout the convention, relating to education, health, work, social inclusion. These two elements should provide enough safeguards against counterproductive measures, be they even well-intended.

Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)

Article 4

1. Adoption by States Parties of temporary special measures aimed at accelerating de facto equality between men and women 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; these measures shall be discontinued when the objectives of equality of opportunity and treatment have been achieved.
2. Adoption by States Parties of special measures, including those measures contained in the present Convention, aimed at protecting maternity shall not be considered discriminatory.

I hope that the language presented would enable the Committee to come to an agreement on this paragraph. I would invite delegations and NGO representatives to approach me at the Liechtenstein desk or via phone (9179576056) or email (sbarriga@un.int) with their views on this proposal.

**Fifth Ad Hoc Committee Meeting
January 24-February 4, 2005**

**Intervention of the Special Rapporteur
On Article 9
"Legal Capacity"**

I have listened with great interest to the discussion on legal capacity and would like to make an observation based on my experience as Special Rapporteur.

I believe it is important to note the strong consensus on recognizing persons with disabilities fully as persons before the law, or having juridical personality or capacity or whatever appropriate terms may be in different legal systems.

Historically that recognition has sometimes been denied to particular groups—we think of slaves or children or in some cases and eras, even women or indigenous peoples. Acceptance as a person before the law ensures the applicability of guarantees of equality and non-discrimination and is a prerequisite for individuals to be fully recognized as subjects of rights.

I note that there is less consensus on how to refer to legal capacity, or the capacity to act in all legal matters.

I have heard many delegates refer to national legislation which does not recognize the capacity of everyone to act or to exercise their juridical or legal capacity. I believe we can all agree that children have such limited legal capacity depending on their age and maturity.

The problem is precisely that too often people with disabilities have been assimilated with children in matters concerning legal capacity. In too many cases national legislation allows disability to justify arguing that a person must be "incapacitated" or seen as having "no capacity". Historically, that has often been the case even for those suffering from disabilities that may effect only, for example, the capacity to communicate, easily views, preferences or decisions.

I would like to call on delegates to remember that we are drafting a new treaty precisely to address the many problems

that existing legal systems present for the enjoyment of human rights by persons with disabilities.

Accepting that all adults should be assumed to have full legal capacity and that persons with disabilities may be merely in need of assistance rather than lacking capacity would reflect our commitment to enshrine in this treaty the principle that persons with disabilities are subjects of rights and not objects of protection.

The assistance needed to exert legal capacity may be very modest—translation of legal documents or proceedings into Braille or sign language for example—or it may be very significant. In extreme cases the assistance required may go beyond support for decision making to become almost, in practice, substitute decision making.

But reaffirming the principle that capacity resides with the person and that the role of support or representation is to respect that capacity to the maximum extent possible would, I believe, represent a fundamental statement that this treaty must make.

The change in terminology and conceptual approach will help us emphasize the need for assistance or support to be based on the principle of the dignity of the persons with disabilities as subjects of rights while ensuring that their interests receive the protection that may be required by different types and degrees of disability.

Non-Paper - February 2, 2005

Facilitator's proposal for a revised Article 9

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as a person before the law.

2. States Parties shall recognize that persons with disabilities are entitled to enjoy legal capacity, on an equal basis with others, in all fields, and shall:

a) ensure that, where support is required in order to exercise that capacity, it is proportional to the degree required, is tailored to the person's circumstances, does not undermine the rights of the person, respects the will and preferences of the person, and is free from conflict of interest and undue influence;

b) ensure that where support requires, as a matter of last resort, the appointment of a personal representative then such action shall only be taken in exceptional circumstances prescribed by law and its use shall be minimized through the active promotion of alternatives;

c) ensure that persons with disabilities have access to effective mechanisms to review arrangements for support, including periodic review and, where appropriate, review by a competent, impartial and independent authority.

**Rebecca Netley
Facilitator for Article 9**

Article 11: Freedom from Torture or Cruel, Inhuman or degrading Treatment or Punishment

Prepared by the International Disability Caucus

Why are forced interventions a form of torture?

Forced interventions meet the definition of torture under the Convention Against Torture.

Torture is:

- An intentional act;
- That causes severe pain and suffering (physical or mental); and
- Done for any reason based on discrimination of any kind.

The required intent is not a specific intent to cause the victim to experience pain or suffering, but a general intent to perform the act knowing that severe pain or suffering is likely to result.

Forced interventions are torture because those who perform such interventions know that severe pain or suffering is likely to result. Examples follow:

- Persons with disabilities may be given medication that can alter their brain irreversibly and may have painful effects; these effects are known by the practitioner administering them but they are perceived to be less severe than the disability itself;
- A father forced his daughter with a disability to undergo sterilization for personal hygiene purposes;
- Women with intellectual disabilities are often sterilized with the aim of “protecting” them from pregnancy in case of sexual abuse; while in fact forced sterilization may actually provoke such cases;
- Sometimes when people with physical disabilities undergo many subsequent surgeries resulting, often times, in multiple disabilities;
- Interventions, like corrective surgery, forced psychotropic medication, electro-shock therapy etc. If the person’s choice is that he/she wants to be different from the non-disabled community, and the person feels that there is no need to undergo a specific intervention, then the Convention should respect their right to freedom of choice. Forced interventions without a person’s consent undermines their ability to achieve self determination and is degrading to an individual.

Issues for IDC Plenary intervention on Thursday afternoon

Article 11, 12 and separate article on medical interventions

Absolute protection from forced interventions aimed at correcting, improving or alleviating an actual or perceived impairment which we define as a form of torture and therefore to be covered in article 11

Protection from non disability related medical interventions in the article on Right to Health (Tina)

Article 13

Sign language as a language (Liisa or Markku)

The need to make all information which is available to the public (be it from public or private entities) made accessible to persons with disabilities (to support Thailand, Namibia, Costa Rica and others on this issue) (Stefan)

Shall we address freedom of thought to be added to this article.

Article 14

Do we need to react to discussions on this article?

Shall we react again to ongoing negotiations on articles 9 and 10 which were already addressed last Thursday.

Supported decision making (the last text prepared by the facilitator continues to include a paragraph about appointing a representative of a disabled person, thus leaving the door open to guardianship laws)

No deprivation of liberty based on disability. Do we know if there is a new version of this article?

IDC should ensure to be asked to speak first (as NGOs) and all IDC delegates should speak as IDC to show that the different statements have been agreed and are supported by all IDC members.

Article 12 – Freedom from Violence and Abuse Prepared by the International Disability Caucus

Persons with disabilities are disproportionately vulnerable to violence and abuse, specifically children and women with disabilities. This is understood to include:

- | | |
|------------------------|---|
| ▪ Hate, | ▪ Physical or mental and emotional or sexual abuse, |
| ▪ Bias, | ▪ neglect , |
| ▪ harassment, | ▪ maltreatment, |
| ▪ victimization, | ▪ violence, |
| ▪ negligent treatment, | ▪ and injury. |

Much of this violence is experienced at the hands of formal and informal caregivers, in the context of regulated service and support environments. For example, caregivers will withhold food or personal items as a form of punishment or as an attempt to alter an individual's behaviour. In addition, continued use of non-therapeutic chemical or surgical sterilization of women with disabilities as young as eleven to alleviate personal hygiene responsibilities of formal and informal caregivers, unfortunately is still a reality in some countries.

Too often violent crimes or violent responses towards persons with disabilities are tolerated in circumstances they would not otherwise be. Acts of violence and abuse are too often couched in terms of "treatment" and "restraint". Many persons with disabilities are subject to physical, chemical and environmental restraints as a means of control. Similar treatment to persons without a disability considered as an assault and would be punishable in a court of law.

It is essential that this Convention recognize the disproportionate vulnerability of persons with disabilities to violence and abuse and take adequate and appropriate steps to protect persons with disabilities from such acts. Recently, a young man with a disability was attacked in a park. He was approached by a group of youth who started pushing him and calling him names. One of the youth poured lighter fluid on the young man and set him on fire. The young man suffered from second-degree burns to his head, ears, neck and chest. He is recovering from his burns but has been scarred for life.

Violence and abuse against persons with disabilities must be recognized as such, and person's perpetrating these acts must be prosecuted. We believe that Article 12 should include a reference to this effect. We would like to draw your attention to the proposed new article on Access to Justice, paragraph 1(e) in the text prepared by the International Disability Caucus. We find that this paragraph is better placed in article 12 and is attached for your reference.

We also believe that with regards to the prohibition of medical experimentation without consent and forced interventions and institutionalization, the Convention must be unequivocal. Such acts are always a violation of the person's mental and physical integrity and it is unacceptable for the Convention to permit forced interventions of any kind.

Article 13: Freedom of Thought, Expression and Opinion

Prepared by the International Disability Caucus

The IDC would like to emphasize that draft article 13 of the Working Group Text seems to focus on issues related to access to information and less on the other aspects of the right to freedom of expression and opinion. We call on delegations to include all aspects of the ICCPR which references elements of freedom of expression and thought in the chapeau and body of article 13.

Why sign languages should be recognized in national legislation

Sign languages are not a method or mode of communication; they are natural languages with their own grammatical structure. To date, 30 countries have recognized sign languages in their national legislations. Most recently, the Government of New Zealand has introduced a Sign Language Bill which should come into force in mid 2005. Acknowledgment of Sign languages as real languages comes from serious difficulties for Deaf people to access government services leading to injustices being experienced by our colleagues. For example, Deaf people reported being denied the use of interpreters in courts leading to a lack of access to justice. In medical settings, the denied use of interpreters may lead to risks of misdiagnosis and lack of informed consent. Furthermore, because sign languages are not recognized on a legislative level, the majority of Deaf children are denied the use of Sign language and cannot receive education in their own language. This results in Deaf children being excluded from education, a fundamental human right.

Why we need to specifically identify Braille in the Convention

Braille is the primary literacy medium for Blind and Deafblind people and is the only mode of communication used for writing and reading. As technology continues to develop alternative modes of communication, Braille will remain fundamental for reading and writing for Blind, Deafblind and partially sighted people. For example, in one's own home, a Blind person uses Braille to mark their spice tins; a practical need that cannot be replaced by technology. For the non-visually impaired community, the idea of removing written text as technology develops would never be supported by society. Therefore, why should it be proposed to remove the script for Blind persons in the case of Braille and replace it with sound technology? Moreover, for Deafblind people, sound technology cannot replace Braille. No country has so far recognized Braille as the legal script for blind persons in their national legislations.

What is augmentative and alternative communication and why it is important

Some persons cannot communicate by speaking or writing because of a physical (e.g. cerebral palsy) or intellectual disability. Our colleagues use augmentative or alternative communication which may include a communication assistant, communication boards, assistive technology or any combination of these modes. This is what enables our colleagues to communicate and, therefore, is essential for the realization of their human rights.

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Draft Article 14: Respect for Privacy, the Home and the Family

Prepared by the International Disability Caucus

14 (1) States Parties to this Convention shall take effective measures to protect the privacy of persons with disabilities, their home, family, communications of all kinds and medical records and their choice to make decisions on personal matters. No person with a disability shall be subjected to arbitrary or unlawful interference with their privacy, and shall have the right to the protection of the law against such interference.

(2) States Parties to this Convention shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to personal relationships, and in particular shall ensure:

- (a) That persons with disabilities are not denied the equal opportunity to experience their sexuality, have sexual and other intimate relationships, and experience parenthood;
- (b) The right of all men and women with disabilities who are of marriageable age to marry on the basis of free and full consent of the intending spouses, and to found a family;
- (c) The right of persons with disabilities to retain fertility and effectively exercise their reproductive rights and to that end shall prohibit practices such as compulsory sterilization and abortion;
- (d) That persons with disabilities have access to reproductive and family planning information and the means necessary to exercise them;
- (e) The rights of persons with disabilities with regard to guardianship, wardship, trusteeship and adoption of children, or similar institutions where these concepts exist in national legislation. For the purpose of guaranteeing these rights, States Parties shall provide appropriate assistance to parents with disabilities in the performance of their child-rearing responsibilities;
- (f) That a child shall not be separated from his or her parents on the basis of their disability

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Article 15: Living and Being Included in the Community Prepared by the International Disability Caucus

Institutionalization undermines human rights:

Too often, institutions are the only option offered to people with disabilities as a place to live. Institutions are places where some of the gravest human rights violations take place for the following reasons:

- A person cannot decide where to live, with whom to room, what and when to eat, or when and how to come and go
- A person loses individuality and becomes part of a system that they have no control over
- A person does not leave the institution to go to the doctor, the barber, school or work; everything happens inside the institution
- A person seldom sees their family
- Because everything takes place inside an institution and away from the public eye, a person is more vulnerable to sexual, physical and/or emotional abuse

In effect a person living in an institution is isolated from the community in a setting where self determination cannot be exercised.

The right to live in the community - for every person

Frequently, the need for support or assistance is used to argue that placement in an institution is necessary, or that the person is ineligible to live in the community in the living arrangement of their choice.

The Convention should correct this misconception, and determine that:

- Every person has the right to be included in the community, regardless of his or her need for support; and, linked with that –
- Every person has the right to receive the assistance to enable them to live in the community – including personal assistance and peer support, and access to information regarding such support services.
- Every person is entitled to determine and direct the support they need. In no case shall support be imposed against the person's will.

As in other articles, there is no "one size fits all formula" for type and level of assistance required. For some, monthly peer support sessions would suffice; for others, daily support may be required. All assistance, services and supports should be provided in a manner that strengthens the autonomy, individuality and dignity of the person with a disability.

31 January

**Draft Article 21
RIGHT TO HEALTH**

States Parties shall:

- a) provide persons with disabilities with the same range and standard of health services as provided other persons, including sexual and reproductive health services;
- b) ensure that all health care, health services and public health campaigns, including alternative health care, are fully accessible for persons with disabilities and are provided without discrimination;
- c) ensure that health services include counselling, peer support and other services including those provided by organizations of persons with disabilities; <not finalized>

<what is the main objective of this paragraph?>

- d) promote the appropriate education and training of health professionals to increase their knowledge and respect for the rights, dignity and needs of persons with disabilities, in line with the principles of this Convention;

<should we say anything about people with disabilities being trained as health professionals?>

- e) ensure that persons with disabilities have access to their unedited health and medical records, and are entitled to give or withhold consent to disclosure of this information to third parties, on an equal basis with others;
- f) ensure that persons with disabilities receive all health and medical information in accessible formats, modes, means and languages;
- g) ensure that persons with disabilities are afforded the opportunity to give or withhold free and informed consent to health services at any point in the course of treatment, on an equal basis with others;
- h) ensure that health care is not rationed on the basis of disability.

- i) promote the participation of persons with disabilities and their organizations at all levels in the commissioning, conduct and management of health ethical codes, health research, preparation and monitoring of health legislation, the formulation of health policies and strategies as well as in the planning, delivery, evaluation and monitoring of all health services. <we could delete this and leave it to the provisions in article 4 and article 18>

1 February 2005

Article 17 Education

1. States Parties shall recognize the right of all girls, boys, young people, women and men with disabilities to a quality education on an equal basis to others. With a view to achieving this right,
2. States Parties shall ensure that:
 - a) no child with disabilities is excluded from free and compulsory primary education on account of his or her disability;
 - b) all children with disabilities are provided with quality literacy and independence skills;
 - c) all persons with disabilities shall have access to early childhood intervention and pre-school education, secondary education, vocational training, higher education, adult education and lifelong learning on an equal basis with others, and to that end appropriate assistance and reasonable accommodation needs to be provided;
 - d) no person with disabilities shall be required to undergo any medical treatment or intervention to correct, improve or alleviate any impairment, or any actual or perceived disability, as a condition for accessing any form of education;
 - e) students with disabilities are explicitly included in all national education and implementation plans, consistent with the same standards and objectives provided for all, taking into account the learning and development needs and rights of persons with disabilities;
3. States Parties shall ensure that the educational system aims to:
 - a) Build a society that is inclusive to all persons, including all girls, boys, young people, women and men with disabilities;
 - b) Recognize the full development of the human potential and sense of dignity and self worth, and the strengthening of respect for human rights, fundamental freedoms and disability as an element of human diversity;

- c) Enable all persons with disabilities to participate fully and effectively in a free and inclusive society;
 - d) Support the development of each individual's personality, talents and abilities to his or her fullest potential;
 - e) Recognize and support individual learning needs of persons with disabilities;
 - f) Respect the right of all persons with disabilities to enjoy and participate in their own culture and language;
4. States Parties shall ensure that all girls, boys, young people, women and men with disabilities have full access to inclusive education in their own community. States Parties shall ensure the full accessible, equal and interactive learning environment for all students with disabilities to gain literacy skills through quality education. To that end, States Parties shall ensure the provision of:
- a) required support, including accessible curriculum, accessible teaching medium and material;
 - b) learning materials through appropriate assistive devices, alternative and augmentative communication means and modes, sign languages, including tactile sign languages, Braille, embossed print and other alternative formats, universally accessible built environment, sign language interpreters, assistance of all kinds, or other reasonable accommodations;
 - c) alternative learning strategies and testing methods;
 - d) specialized training programs providing training of teachers and staff, in pre- and in-service training;
 - e) provide continuing education and training programs for teachers who teach students in sign language, tactile sign language, Braille and other communication modes and means, relevant to the specific needs of those students;
 - f) education in daily life skills and mobility training in parallel with the academic education for blind, partially sighted and deafblind children and young persons, including the right to choose education in special

schools or groups of their own during primary education, consistent with other provisions in this article;

- g) multilingual education in sign language through deaf and hearing teachers who are fluent in sign language for deaf and deafblind students, including the right to choose education in special schools or groups of their own, during primary education, consistent with other provisions in this article.