OBSERVATIONS ON THE PROCESS OF ELABORATING A NEW HUMAN RIGHTS INSTRUMENT ON THE RIGHTS OF PERSONS WITH DISABILITIES

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INTRODUCTION

The process within the United Nations considering proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities has reached a stage in which several proposals and other remarks have been made on the subject. A wide range of actors have made their statements on the subject.

The purpose of this report is to explore the core proposals on the subjects which are in the sphere of this report considered essential. The idea is not to come up with a comprehensive list but to give certain examples which reflect the predominant characteristics of the process and to describe those characteristics.

As we are developing a new instrument having a better effectiveness as a goal it might be beneficial to keep as a model some instruments over which at least some level of global agreement has been already reached. It is easier to discuss different themes if something already agreed on is taken into consideration. Of course there are certain matters that have to be reconsidered after few years have gone by. Also while we are now discussing a different kind of a human rights instrument – a legally binding one – we have to remember that rights must be somehow enforceable.

Especially in the context of human rights of persons with disabilities The Standard Rules on the Equalization of Opportunities for Persons with Disabilities\(^1\) plays a major role in the discussion and has to some extent politically binding characteristics. The Standard Rules has many merits. It is concise and provides a concentrated presentation of guidelines in a number of areas. These guidelines have been used in a great number of countries in many different ways. The fact that the recommendations are at the international level has created room for national application and adjustment to regional and local circumstances.\(^2\)


The Standard Rules are not a result of a sudden achievement, but a slow process. The themes of the Standard Rules and wording of its various paragraphs have been discussed thoroughly at that time. Of course it was over ten years ago when this discussion took place. Some short-comings have been identified in the Standard Rules and therefore the Special Rapporteur of the Standard Rules has in its report proposed a supplement to the Standard Rules.

On the future role of the Standard Rules could be said that firstly it is an instrument that could continue to play a highly useful role also after the adoption of a legally binding instrument and as a valuable reference document when applying legally binding human rights instruments and secondly it is an instrument that could now serve as a starting point for the discussion that is going on around the process on a new human rights instrument.

Besides existing disability-specific instruments, among others the Standard Rules, the general human rights sphere has recognized disability as a human rights issue. The material and the jurisprudence related to this phenomenon is of most significant importance for our purposes. It is important to have arguments that are also legally on a solid ground.

International recognition of disability as a human rights issue is increasing and disability-related questions are today concerns for the human rights bodies of the United Nations.

Recently, resolutions of the United Nations Commission on Human Rights have established ever closer links between the disability issue and the operation of the United Nations human rights machinery. For example the 1998 resolution defines infringement of the human rights of persons with disabilities with the help of the Standard Rules. Overall the resolutions of the Commission today stress the importance of the core human rights instruments in the context of disability.
The six core human rights instruments and their application provide some starting points to the discussion on a new human rights instrument.

In the case of the ICCPR it seems that the general awareness of the applicability of the convention to persons with disabilities needs to be developed. However, some general comments adopted by the Human Rights Committee include reference to disability. Also a number of individual complaints have resulted in views relevant for our purposes. 11

The ICESCR has tremendous potential in the context of disability and the material related to it should be taken into consideration. In General Comment No. 5 of the Committee on Economic, Social and Cultural Rights 12 the Committee examines disability as a human rights issue. General Comment No. 5 could be described as a milestone in the process of developing disability as a human rights issue. 13

Also the four other core human rights instruments and material on their monitoring include beneficial elements useful for our purposes. The dimensions of the six core human rights instruments are thoroughly studied in a research directed by Theresia Degener and Gerard Quinn 14. The substance and conclusion of this research had been widely recognized throughout the disability world and it can today be considered as one of the most valuable source of disability as a human rights issue.

E/CN.5/2002/4, paras. 42-45. See also other resolutions of the Commission on Human Rights of Persons with Disabilities listed in the Documents-section.


13 Bruce & Quinn & Padraic 2002, p. 82 argue that states parties should be actively encouraged to apply the letter and the spirit of General Comment No. 5 when compiling their periodic reports. See also See Report of the Special Rapporteur of the Commission for Social Development on monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities on his third mandate, 2000-2002, E/CN.5/2002/4, paras. 41 and 62.

14 The Convention on Protection of Rights of Migrant Workers entered into force after the research.
In addition to the Standard Rules and the six core human rights conventions there are several other sources outside the UN-process itself that we can refer to as models of dealing with some of the issues. For example the Inter-American Convention on the Elimination of all Forms of Discrimination against Persons with Disabilities\textsuperscript{15}, Americans with Disabilities Act or the EU Directive establishing a general framework for equal treatment in employment and occupation\textsuperscript{16} provide some lead on subjects discussed.

Also some workshops have been carried through on the subject and different declarations and recommendations have been published in addition to the discussion.

1. Definition of Disability

1.1. General Remarks

The definition of disability is a complex issue. The matter seems to be that every actor can come up with a suitable definition depending on the context. Proposals of the definition of disability can even vary on the context even if the presenter of the definition might be the same.

One topic seems to be whether to define the term “disability” or the term “person with disability”. In the sphere of this report it is unnecessary to deepen this contradiction and therefore these two concepts are understood as referring to the same situation.

The reason why this topic is discussed generally seems to be primarily that if the term “person with disability” is used, disability is seen as an element of a person that excludes all other facets of a person. This observation is of course valid but for the purposes of a legal instrument it is necessary that the definition is clear and to some extent the definition must be anchored to the characteristics of a person. It is not possible to describe disability only as a relation between a person and environment.

The proposals below use variably the notions of “disability” and “person(s) with disability(ies)”. However it seems to be that the focus within this subject is on the contents of the definition, not the

\textsuperscript{15} AG/RES. 1608 (XXIX-O/99), June 7 1999.

title. It seems evident that first we have to define disability and after that we can assume that “person with disability” or “disabled person” is a person who has or who experienced the before mentioned characteristics.

The variation in the definitions of disability seems to be primarily in the way the relation of individual and environment is seen as a prerequisites of a disability.

1.2. Alternative Solutions

**The Inter-American Convention:** The term "disability" means a physical, mental, or sensory impairment, whether permanent or temporary, that limits the capacity to perform one or more essential activities of daily life, and which can be caused or aggravated by the economic and social environment.\(^{17}\)

Comment: The definition of the Inter-American Convention is a model for the Mexican proposal.

**The Mexican Draft:** Disability means a physical, mental (psychic), or sensory impairment, whether permanent or temporary, that limits the capacity to perform one or more essential activities of daily life, and which can be caused or aggravated by the economic and social environment.\(^{18}\)

Comment: The Mexican proposal acknowledges the role of environment as a prerequisite of disability but still has weight on the characteristics of an individual.

**Venezuela:** Persons with disabilities means persons with any form of physical, intellectual or sensory absence or impairment, whether structural, functional or both, which constitutes a permanent or temporary limitation, restriction, obstruction or dysfunction in respect of human beings' relationship to their environment that may be caused or aggravated by the economic and social environment.\(^{19}\)

\(^{17}\) Inter-American Convention On the Elimination Of All Forms of Discrimination Against Persons With Disabilities, art. 1.


Comment: The Venezuelan proposal stresses more than the Mexican the environmental aspect in the definition of disability.

**EU Element paper (2nd meeting):** The European Union believes that for the purposes of the Convention it is not necessary to define the notion of disability.\(^{20}\)

Comment: Some actors had made statements that the definition or the notion of disability is not to be dealt with at this stage or at all.

**EP:** Believes that the definition of disability should cover all persons with disabilities, irrespective of the level of severity, define disability as the interaction of a person with an impairment and the social barriers, both environmental and attitudinal, (...)\(^{21}\)

Comment: However, a later resolution of the European Parliament defines disability rather widely. It pays attention to the role of environment but has at least one factor that reflects the medical model of disability. It talks about severity of the disability which keeps the attention to the characteristics of a person not the relation with the surrounding environment.

**EDF:** The definition of disability is a very complex issue and should not become an excuse for inaction. We therefore suggest not to deal with this issue at an early stage of the process.

The new WHO classification International Classification of Functioning (ICF) is not a legal definition of disability and therefore not appropriate for a legal instrument.\(^{22}\)

Comment: EDF argues that the WHO classification\(^{23}\) is not appropriate for the purposes of a legal instrument.

\(^{20}\)“Elements for an international convention”. A/AC.265/2003/CRP.13/Add.2. (Hereafter referred to as “EU Element Paper”).


\(^{22}\)NGO contributions to the elements of a convention. A/AC.265/2003/CRP.13/Add.1. (Hereafter referred to as “EDF”).

Even though EDF considers it as very important that:
- the prohibition of discrimination should cover all persons with disabilities, with significant impairments, irrespective of the level of severity.
- for a person to be considered disabled, the person has to view him or herself as a person with a disability.
- the diversity of the disability population must be acknowledged.
- the parents, spouses and siblings of persons with disabilities, in particular of disabled children and persons with disabilities unable to represent themselves, must also be protected by the Convention.

\(^{23}\)International Classification of Functioning, Disability and Health (ICF). World Health Assembly resolution WHA 54.21, 22 May 2001.
DPI JAPAN:

1. Definition of "disability"

For the purposes of this Convention, "disability" shall mean difficulties experienced, due to a social environment requiring some degree of ability and specific skills, without taking into account individual particularities related to, inter alia, injury or sickness.

2. Definition of "persons with disabilities"

(1) For the purposes of this Convention, "persons with disabilities" shall mean people who are in such a situation, that they experience, or might experience, difficulties in living, due to a long-term, temporary or future disability. "Persons with disabilities" shall mean people in such a situation that they are disadvantaged if compared to non-persons with disabilities, unless the environment undergoes adaptation measures to their disabilities.

(2) For the purposes of this Convention, "persons with disabilities" shall mean people having in the past experienced "disabilities" as defined at paragraph 1, or considered as experiencing "disabilities".24

Comment: The proposal of DPI Japan has a two-fold structure. First it describes “disability” in a way which is rather environmentally oriented and after that gives two alternatives to the definition of “persons with disability”. The solution of alternative nr. 2 seems rather logical and together with paragraph one it gives a compact definition of persons with disabilities and helps to explore the scope of application of a possible future convention.

The Bangkok Draft:

The Bangkok Draft offers three alternatives of the definition of disability.25

Proposal A

"disability" is the dynamic interaction between the medical or health condition of a person and the social, economic and physical environment, and involves the limitation of the person's opportunities to participate in one or more life activities, which results from [or is aggravated by] the interaction between the environment and the person's physical, sensory, psychological, developmental, learning, neurological or other impairment (including the presence in the body of an organism or agent causing malfunction or disease)

Proposal B

"disability" is a dynamic interaction between a person's physical, sensory, psychological, developmental, learning, neurological or other impairment (including the presence in the body of an organism or agent causing malfunction or disease) and the social, economic and physical environment, which results in the limitation of a person's opportunities to participate in one or more life activities

Proposal C

"disability" is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, social, attitudinal and cultural barriers encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairment (including the presence in the body of an organism or agent causing malfunction or disease), which may be permanent, temporary, episodic or transitory in nature

Comment: All three of the alternatives described in the Bangkok Recommendations stress the role of participation in the definition of disability.

1.3. Conclusions

As the examples above clarify the definition of disability is open to a wide range of interpretations. There is at the time no consensus on the subject among actors. The question of definitions of disability, person with disability or disabled person however seems to be a question that has to be concluded rather quickly to move on with the discussion on the substantive matters.
The definition is crucial in the context of the scope of application of the future convention. One has to be aware of which type of situations the convention is applied to. This is extremely important for states because they have to know which obligations a new convention will produce and which actions they have to take in the scope of their legislation.

A few key issues on the definition could be summarized for future discussion:

(i) As discussed above the Standard Rules is something that has been widely recognized both at the time of adoption and afterwards. It would help to speed up the discussion if we have something familiar to start the discussion with. The most important aspect that the Standard Rules reflect on the definition of disability is the role of participation\textsuperscript{26}. The notion of participation moves the center point of definition from purely individual characteristics to the relationship between individual and environment. The notion of participation is the carrying principle in the Standard Rules.

(ii) In close connection with the first issue is that the definition has to recognize both the individual characteristics of a person and the environment. Defining disability only with the help of the relationship between individual and environment may lead to a definition that makes the application of the convention difficult due to the expanding of the scope of definition outside of what is purported\textsuperscript{27}.

\textsuperscript{26} The Standard Rules, paras 17 and 18 state:
"The term "disability" summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.

The term "handicap" means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between the person with a disability and the environment. The purpose of this term is to emphasize the focus on the shortcomings in the environment and in many organized activities in society, for example, information, communication and education, which prevent persons with disabilities from participating on equal terms."

The Standard Rules uses the terms “disability” and “handicap”. For our purposes these terms together build a definition which could be a starting point of discussion. The substance of the definition of the Standard Rules is in harmony with some of the proposals made by actors, especially the Bangkok Recommendations.

\textsuperscript{27} The Standard Rules describes this in its Introduction, para 22: "As a result of experience gained in the implementation of the World Programme of Action and of the general discussion that took place during the United Nations Decade of Disabled Persons, there was a deepening of knowledge and extension of understanding concerning disability issues and the terminology used. Current terminology recognizes the necessity of addressing both the individual needs (such as rehabilitation and technical aids) and the shortcomings of the society (various obstacles for participation)."
(iii) One question relating to the definition is the role of families and relatives of persons with disabilities. It has to be kept in mind that persons with disabilities themselves are the stakeholders when we are talking about their human rights. The role of families and relatives may be discussed in the sphere of the definition. In this case we are talking about whether the families and relatives are per se in the scope of application. This kind of thinking is not a recommendable one in the framework of modern disability politics.

(iv) Diversity of disability
The diversity of disability should be recognized. A new instrument should recognize all disabilities and also recognize the varying duration of disability. Also all ages of persons with disabilities should be covered by a new convention.28

2. Substantive Provisions

2.1. General Remarks

Proposals and themes overall on the substantive provisions seems to be two-fold.

For the first the notion of discrimination is seen as the key question in the context of human rights of persons with disabilities. Equality and non-discrimination are at the very heart of modern human rights law29. The notion of discrimination is in the proposals and in the discussion of the Ad hoc committee dealt in such a high priority that it could be interpreted that a new human rights instrument would be based on a broad and far-reaching non-discrimination approach. Therefore the question of discrimination and the discussion taking place now should be clearly reflected in drafting process of a new human rights instrument.

28 The Special Rapporteur of the Standard Rules points out this question in its proposal for supplement of the Standard Rules (Report of the Special Rapporteur of the Commission for Social Development on monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities on his third mandate, 2000-2002, annex), paragraph 3: “Throughout the entire Standard Rules text, the term “persons with disabilities” is used to refer to persons of all ages with disabilities. In the text of the proposed supplement the term should always be understood as meaning “girls, boys, women and men with disabilities” when no other qualifying term is indicated.”

29 Hendriks 1995, p. 40 describes the conceptual misunderstandings relating to this context.
Discrimination is not simply a question of specific examples of individuals discriminating against disabled people. A narrow understanding of discrimination presupposes that a comparison can be made between two situations or categories of individuals. A broader definition is essential and also in the context of persons with disabilities we need to have a broader concept of discrimination.

As we are exploring discrimination in the context of disability we have to start with distinguishing between two types of equality, formal and material equality. As counterparts to these are direct discrimination and indirect discrimination.

First there is formal equality and its counterpart direct discrimination. It means equality before the law. Formal equality pays attention to the equality of treatment. It requires that the law treats persons who are situated alike similarly. That formal equality is guaranteed as an independent right is immediately visible for example in the International Covenant on Civil and Political Rights (ICCPR). As an example of direct discrimination in the context of disability could be mentioned situations where entry of a person with disability into a restaurant is denied on the basis of disability.

Secondly there is material equality and indirect discrimination. Material equality highlights inequality arising in the structures of societies. Material equality moves the attention to the equality of result instead of equality of treatment. The Concept of indirect discrimination as such cannot be found in any legally binding human rights instrument although it can very well be said to be included in existing prohibitions of discrimination. Therefore it is today necessary to make a textual interpretation of the various treaties as well as to examine the case law by treaty-based monitoring bodies. However certain treaty provisions of the existing human rights conventions and also proposals made on a new human rights instrument on rights of persons with disabilities use a wording that describes the core substance of indirect discrimination.

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30 Barnes 2000, p. 3.
31 Frostell 1999, p. 29.
32 Hendriks 1995, p. 46.
33 General Assembly resolution 2200A (XXI) of 16 December 1966. Article 26 of ICCPR states that “All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.
34 Frostell 1999, pp. 44-45.
35 See e.g. International Convention on the Elimination of All Forms of Racial Discrimination (General Assembly resolution 2106 (XX) of 21 December 1965), art. 1: “In this Convention, the term "racial discrimination" shall mean any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has
In the case of *Althammer vs. Austria* the concept of indirect discrimination is used. The Human Rights Committee states in the communication that “the Committee recalls that a violation of article 26 can also result from the discriminatory effect of a rule or measure that is neutral at face value or without intent to discriminate.” The adoption of this kind of an interpretation shows that even if the wording of a non-discrimination clause primarily addresses direct discrimination the scope of prohibited discrimination should be understood to be a wider one. Besides the legal consequences this helps us to understand the concept of discrimination in a wider meaning.

We can still continue to extend the concept of indirect discrimination and understand failure to treat differently situations that are different as indirect discrimination. The European Court of Human Rights (ECHR) uses this kind of extension in the case of *Thlimmenos vs. Greece*. In the case ECHR states that: “The right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention is also violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different.”

This type of wide understanding of indirect discrimination is crucial to understand in the context of human rights of persons with disabilities. Usually positive measures are needed to realize the full enjoyment of human rights of persons with disabilities. This applies both to civil and political rights and economic, social and cultural rights. The principles reflected in the *Thlimmenos* –case could be interpreted so that positive measures can be seen as a duty and not merely as allowed by non-discrimination provisions.

Indirect discrimination can in wider meaning cover also institutional discrimination.

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37 Paragraph 10.2.
39 Paragraph 44.
40 Barnes 2000, p. 3 describes institutional discrimination: “Institutional discrimination is embedded in the work of contemporary welfare institutions, and is present if they are systematically ignoring or meeting inadequately the needs of disabled people compared with able-bodied people. It is also present if agencies are regularly interfering in the lives of disabled people as a means of social control in ways, and/or to an extent, not experienced by able-bodied people. It is therefore a descriptive concept related to outcome.”
For the second it seems rather common that a comprehensive list of other substantive human rights, both civil and political and economic, social and cultural rights is introduced in the proposals.

There is a solid connection between the broadness of the non-discrimination clause and on how comprehensive list of other substantive provisions is needed. The broadness of a non-discrimination clause can be seen to determine how long a list of other substantive provisions a new human rights instrument would need to include. If the non-discrimination clause as such or its predicted interpretation practice is wide enough and covers the prohibition of indirect discrimination in its all forms the list of other substantive provisions could be a shorter one and pinpoint comprehensively the rights that are regarded as the most important in the context of discrimination against persons with disabilities.

2.2. Alternative Solutions on the Concept of Discrimination in the Context of Disability

The Inter-American Convention: The term "discrimination against persons with disabilities" means any distinction, exclusion, or restriction based on a disability, record of disability, condition resulting from a previous disability, or perception of disability, whether present or past, which has the effect or objective of impairing or nullifying the recognition, enjoyment, or exercise by a person with a disability of his or her human rights and fundamental freedoms.\textsuperscript{41}

The Mexican Draft: Discrimination against persons with disabilities means any distinction, exclusion, or restriction based on a disability, record of disability, condition resulting from a previous disability, or perception of disability, whether present or past, which has the effect or objective of impairing or nullifying the recognition, enjoyment or exercise by a person with a disability of his or her human rights and fundamental freedoms.

The Venezuelan Draft: Discrimination against persons with disabilities means any distinction, exclusion or restriction on social participation, based on a disability which has the effect of

\textsuperscript{41} Inter-American Convention On the Elimination Of All Forms of Discrimination Against Persons With Disabilities, art. 1.
impairing or nullifying the recognition, enjoyment or exercise by a person with a disability of his or her human rights and fundamental freedoms in the political, economic, social, cultural, employment, educational, sports or any other sphere of public life.

**EU Element Paper**: For the purpose of the present Convention, a definition of direct and indirect "discrimination on the grounds of disability" is needed. EU element paper also proposes addressing the issue of reasonable accommodation.

**European Parliament**: the definition of discrimination should broadly reflect the one used in Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation and include direct and indirect discrimination, reasonable accommodation (adjustments) and harassment;

**EDF**: Direct discrimination, indirect discrimination and harassment need to be considered as forms of discrimination. Moreover, it is vital to ensure that the failure to provide reasonable accommodation, has to be considered as a form of discrimination.

**DPI-Japan**: Definition of "discrimination against persons with disabilities"

(1) For the purposes of this Convention, "discrimination against persons with disabilities" shall mean situations, in a political, economical, social, cultural or any other context related to living conditions, and in which, people’s right to equal access to social life is denied or limited, because of their physical or psychological particularities.

(2) (…)

1. For the purposes of this Convention, "unintentional discrimination” shall mean situations in which, due to ignorance, incomprehension or prejudice against persons with disabilities, administrative services, public or private sectors, or individual deny actual violations of the rights of persons with disabilities, or, in which the specific needs related to a disability are not given adequate consideration, and as a result persons with disabilities are disadvantaged or suffers from ill-treatment.
The Bangkok Draft

“discrimination on the ground of disability” includes:

(1) any distinction, exclusion, restriction on the ground of disability which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise of human rights and fundamental freedoms in the political, economic, social, cultural, civil[, linguistic] or any other field;

(2) any act, criterion, provision, practice, policy, rule or arrangement which, although not explicitly based on disability—
   (a) [has a disproportionate impact on persons with disabilities or persons with particular disability;]
   (b) has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise of their human rights and fundamental freedoms in the political, economic, social, cultural, civil [, linguistic] or any other field; and
   (c) cannot be objectively justified as a reasonable and proportionate means of achieving a legitimate aim;

(3) a failure to make reasonable accommodation, a failure to eliminate environmental and attitudinal barriers, or the establishment of the new barriers which impair access to desired services and full participation in the activities of civil, cultural, economic, political and social life,

(4) failure to provide goods, services or facilities to persons with disabilities [in the most appropriate manner for ] [in the most inclusive setting appropriate to the needs of] those persons,\(^{42}\) or

(5) less favourable treatment of an associate of a person with a disability because of that other person’s disability or because of the association. (…)

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\(^{42}\) Participants expressed concern that any formulation adopted should respect the goal of full inclusion of persons with disabilities and the right of persons with disabilities to choose the most appropriate manner for receiving services, and should not permit or encourage States to adopt separate or segregated provision of goods or services in a manner not conducive to the full realization of the rights of persons with disabilities.
2.3. Alternative Solutions on Other Substantive Rights

In many proposals there is a large number of rights listed\textsuperscript{43}. It seems evident on the basis of proposals that the full range of human rights is needed in a new instrument. This means including both civil and political rights and economic, social and cultural rights. Especially in the context of rights of person with disabilities one has to remember that these two sets of rights are closely interrelated. The realization of civil and political rights requires some level of realization of economic, social and cultural rights. This means that if we discuss about a convention with a non-discrimination approach it does not mean that for example social rights and social development would be left out of the scope of application.

However one should not at this stage drown the discussion on substantive rights with numerous lists of specific rights but rather to focus on identifying and remediying obstacles for full enjoyment of rights which have a special role in the context of human rights of persons with disabilities\textsuperscript{44}. There are certain typical areas of life where the most significant violations of human rights of persons with disabilities take place. This is not undermining of any other rights but if the goal is to achieve a more effective realization of human rights in whole one has to examine thoroughly in which areas of life the most indisputable human rights violations take place.

Once again, the Standard Rules could act as an example. The first two chapters of the Standard Rules\textsuperscript{45} could give some direction on what areas of life should be covered and protected as human rights in a new instrument. Of course the Standard Rules are a bit too concrete to be directly converted into a human rights norm but the spirit of the Standard Rules and its expression in single rules reflects the areas which have been in near past been considered as essential.

\textsuperscript{43} See e.g. DPI Position Paper Regarding a New International Human Rights Convention for Disabled People (available from http://www.un.org/esa/socdev/enable/rights/contrib-dpi.htm), that lists 25 proposals of substantive rights a convention should include (non-discrimination being one of these). As another example a long list of rights is presented in the Bangkok Draft.

\textsuperscript{44} An example of information overflow can be seen in the paper: “NGO contributions to the elements of a convention A/AC.265/2003/CRP.13/Add.1. (available from: http://www.un.org/esa/socdev/enable/rights/a_ac265_2003_crp13_add1.htm).

\textsuperscript{45} I. Preconditions for Equal Participation, II. Target Areas for Equal Participation.
2.4. Conclusions

A good presentation of the possibilities on the structure of substantive provisions on a new convention is presented in the note of Secretary General\textsuperscript{46}. Secretary General suggests on the grounds of the experience of the United Nations system with existing conventions three models for the \textit{Ad hoc} –committee to consider: a holistic rights model (Convention on the Rights of the Child); a non-discrimination model (Convention on the Elimination of All Forms of Discrimination against Women and Convention on the Elimination of All Forms of Racial Discrimination); and a hybrid model, combining social development and human rights elements.

\textit{Holistic model}

The term holistic model means that a convention would include all categories of human rights – civil, political, economic, social and cultural – that are applicable to persons with disabilities. Although those rights are based on existing human rights applicable to all human beings, those that would be stipulated in a new convention would be more specifically tailored to the needs of children. A new convention would also include rights that are only applicable to persons with disabilities.

\textit{Non-discrimination model}

According to this model a new convention would not provide specific rights accorded only to persons with disabilities. A convention would reaffirm the universal human rights of persons with disabilities, and focus on how discrimination impedes their equal enjoyment of universal rights and how to ensure that persons with disabilities can enjoy the human rights guaranteed in other instruments. A convention would be instrumental in defining the concept of discrimination by identifying specific areas where discrimination is likely to occur and specifying appropriate measures to eliminate it.

Hybrid model

The hybrid model would include elements of both the holistic and non-discrimination models.

The principles of non-discrimination and the application of all existing human rights to persons with disabilities would form the basis of a convention, which would also include recommendations to develop and guarantee special rights in areas specifically relevant to the situations and needs of persons with disabilities, such as employment, education, treatment and rehabilitation.47

To sum up we could develop the hybrid model described above a bit and draw following conclusions on how the substantive provisions could appear in a new convention.

(i) Full enjoyment of existing human rights should be particularly stated. Persons with disabilities should enjoy the realization of all existing human rights which are guaranteed under the seven core human rights conventions48. This could be stated perhaps in preamble although it is a substantive matter.

(ii) A broad and far-reaching non-discrimination approach is emphasized. Indirect discrimination understood as widely as described above in chapter 2.1. moves the weight in developing a new human rights instrument clearly to the non-discrimination approach. This seems to be at least the intent in most of the proposals and in some it is explicitly mentioned. The non-discrimination clauses would be the leading factor in a new instrument.

(iii) A comprehensive list of human rights of which the enjoyment must be effectively protected especially for persons with disabilities. An example of this kind of practise can be found for example in the International Convention on the Elimination of All Forms of Racial Discrimination (CERD)49. In article 5 of CERD is a comprehensive list of rights which have been regarded as rights having a special status in the context of racial discrimination.

47 Ibid. paragraphs 68-72.
49 General Assembly resolution 2106 (XX) of 21 December 1965.
3. Monitoring Mechanisms

3.1. General Remarks

The role of monitoring is of most importance while thinking about the final outcome of the process going on. As we think about a new instrument on the rights of persons with disabilities we should in any case not undermine the potential that the existing human rights instruments have.

When transforming disability into a human rights issue it becomes even more important to utilize also the existing instruments. It will take years to draw up a new human rights instrument for persons with disabilities. Meanwhile the use of the existing instruments is of the most fundamental value and promotes the new way of thinking in the context of human rights of persons with disabilities. Even if a new convention is adopted in the future, it will still be necessary to obtain maximum advantage from the existing human right instruments.50

Four of the core human rights treaties (ICCPR, CAT, CERD, CEDAW) establish procedures which allow individuals to submit complaints to the treaty monitoring bodies (The MWC includes a similar procedure but none of the relatively few states that have ratified the convention have accepted the right of complaint. Regrettably, only few complaints relating to disability issues have been received to date, and even fewer have passed the admissibility stage. However, these existing cases demonstrate the potential of the individual complaint mechanism in promoting and protecting the human rights of persons with disabilities and facilitating the tailoring of general human rights norms to the specific situation and needs of persons with disabilities.51 This is of course true also in relation to a larger number of cases that have addressed, for example, discrimination or linguistic rights or rights of participation, although not specifically in the context of disability.

3.2. Alternative Solutions

**Monitoring body**

**The Mexican Draft:** In order to monitor the implementation of this Convention, a Committee of Experts on the Rights of Persons with Disabilities (hereinafter, "the Committee") shall be established, the functions of which shall be as follows: (…)\(^{52}\)

**The Venezuelan Draft:** In order to monitor the implementation of this Convention, a Committee of Experts on the Rights of Persons with Disabilities (hereinafter called "the Committee") shall be established, (…)\(^{53}\)

**EU Element Paper:** The issue of the monitoring mechanism will have to be revisited in light of the outcome of negotiations of this convention and the ongoing review of all human rights treaties monitoring mechanisms.\(^{54}\)

**European Parliament:** (...)Believes that a UN Monitoring Committee on the Rights of Persons with Disabilities (…) should be established as a strong and effective monitoring system (…).\(^{55}\)

**IDA:** Since the Disability Convention shall be a human rights instrument the monitoring mechanism should be similar to that for the existing six core Human Rights Treaties (especially CEDAW and CRC).\(^{56}\)

**The Bangkok Draft:** For the purpose of reviewing the implementation of this Convention, there shall be established a Committee on the Protection of the Rights of Persons with Disabilities (…).\(^{57}\)

**Composition of the monitoring body**

**The Mexican Draft:** The Committee shall consist of 12 experts (men and women) chosen from among prominent national leaders of organizations of persons with disabilities, scholars, specialists, scientists, and doctors of recognized high moral integrity and competence in the protection and

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\(^{52}\) The Mexican draft, art. 20.

\(^{53}\) The Venezuelan draft, art. 23.

\(^{54}\) The EU Element Paper, part V.


\(^{56}\) IDA, Statement for 2nd Ad Hoc Committee Session, June 2003, part IV.

\(^{57}\) The Bangkok Recommendations, art. 37.
promotion of the rights and dignity of persons with disabilities and who shall serve in their personal capacity.\textsuperscript{58}

**The Venezuelan Draft:** The Committee shall consist of 12 experts of high moral standing and recognized competence in the area of protection and promotion of the rights and dignity of persons with disabilities, serving in their personal capacity.\textsuperscript{59}

**EU Element Paper:**

**European Parliament:** (…) Committee (…) should be composed of a majority of disabled people.\textsuperscript{60}

**IDA:** (…) In addition the monitoring process should have the benefit of the involvement of the Special Rapporteur and the panel of experts throughout the monitoring process.\textsuperscript{61}

**The Bangkok Draft:** The Committee shall consist, at the time of entry into force of this Convention, of [10], [12], [18] experts of high moral standing, impartiality and shall have a recognized competence in the field covered by the Convention.\textsuperscript{62}

**Mandate of the body**

**The Mexican Draft:**

a) Evaluate the national reports submitted periodically by States Parties on the progress and problems encountered in implementing this Convention.

b) Make recommendations of a general nature to States Parties to further advance the implementation of this Convention.

c) Invite specialized bodies, other competent agencies, and non-governmental organizations to participate in studying the implementation of this Convention.

\textsuperscript{58} The Mexican draft, art. 22.
\textsuperscript{59} The Venezuelan draft, art. 23.
\textsuperscript{61} IDA, Statement for 2nd Ad Hoc Committee Session, June 2003, part IV.
\textsuperscript{62} The Bangkok Recommendations, art. 37.
d) The Committee may invite specialized bodies and other agencies of the United Nations to submit reports on the implementation of the provisions of this Convention which apply to their particular sphere of competence.

e) Identify areas of cooperation among States Parties, and between these and specialized bodies and competent agencies that facilitate implementation of this Convention. To this end, the Committee shall submit its recommendations to the Conference.

f) The Committee may recommend technical assistance from United Nations agencies at any stage of the report evaluation process or during the implementation of its final recommendations.

g) Submit an annual report to the United Nations General Assembly on its activities pursuant to this Convention and make suggestions and recommendations based on the study of the reports and data provided by States Parties. 63

The Venezuelan Draft:

1. The Committee's functions shall be to evaluate the national reports submitted annually by States parties on the progress and difficulties in implementing this Convention and make specific recommendations to States parties, specialized agencies and other competent organs further to advance the implementation of this Convention.

2. The Committee shall identify areas of cooperation among States parties, and between these and the specialized agencies and other competent organs, that will facilitate implementation of this Convention. To that end the Committee, after evaluating the national reports, shall transmit its recommendations to the States parties and to the representatives of the specialized agencies and other competent organs.

3. The Committee may transmit to the specialized agencies and other competent organs, reports of States parties that contain requests for financial and technical assistance, together with the Committee's observations and suggestions.

63 The Mexican Draft, art. 20.
4. In order to identify progress and difficulties in implementing this Convention and make specific recommendations to States parties, specialized agencies and other competent organs, the Committee shall invite the specialized agencies, other competent organs and non-governmental organizations to participate in studying the implementation of this Convention and to make recommendations thereon.

5. The Committee may seek technical assistance from United Nations organs at any stage of the report evaluation process or during the implementation of its final recommendations.

6. The Committee shall submit an annual report to the States parties and to the General Assembly of the United Nations on its activities pursuant to this Convention.64

**EU Element Paper:** -

**European Parliament:** (...) should be established as a strong and effective monitoring system to identify measures to enhance and surmount obstacles to proper implementation of the Convention by:

- evaluating reports submitted periodically by States Parties and NGOs on the progress and problems encountered in implementing the Convention and making recommendations to these States,

- identifying areas of cooperation among States, and between them and competent agencies that facilitate implementation of the Convention,

- receiving complaints from individuals or NGOs and responding to requests for independent enquiries;65

**IDA:** This will entail state reports, complaint mechanisms (individual/group and state), NGO involvement and investigation powers of the treaty monitoring body. In addition the monitoring

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64 The Venezuelan Draft, art. 24.
process should have the benefit of the involvement of the Special Rapporteur and the panel of experts throughout the monitoring process.66

The Bangkok Draft:

The Bangkok Draft includes reporting by states parties (art. 38-39).

It also gives a state party to the Convention possibility to declare that it recognizes the competence of the Committee to receive and consider communications from or on behalf of individuals subject to its jurisdiction who claim that their individual rights as established by the present Convention have been violated by that State Party. (art. 41-45)

Also a possibility of Inquiry Procedure is introduced in the Bangkok Recommendations. (art. 46-48)

3.3. Conclusions

On the basis of the above mentioned proposals and other material presented during the process the following may be stated:

(i) It seems rather clear that the majority of actors would like to see a committee on the protection of the rights of persons with disabilities. As a UN body it would be similar to the monitoring mechanisms of the existing human rights conventions.

(ii) Different kind of proposals have been made on the composition of a committee. The main theme seems to be that the it is necessary to include people with disabilities themselves or through the organizations of persons with disabilities in the monitoring body. This is an important aspect and it has been widely accepted also among the member states. Also for example the role of the national human rights institutions, the Special Rapporteur of the Standard Rules and doctors of recognized high moral integrity and competence have been proposed as part of a monitoring body. Some of the proposals suggest a body of experts, based on the individual competence. Being an

66 IDA, Statement for 2nd Ad Hoc Committee Session, June 2003, part IV.
expert would presumably be interpreted so that an expert would be a person who has some status mentioned above in this paragraph.

(iii) The mandate of proposed body could be divided into three main parts.

Firstly the evaluation of periodical States Parties reports on the progress and problems encountered in implementing this Convention would be one of the major missions of a body.

Secondly a committee would be mandated to receive complaints from individuals, NGO’s and states.

Thirdly an inquiry procedure is introduced as a mandate of a committee. The Bangkok Recommendations proposes on the inquiry procedure e.g.: “If the Committee receives reliable information indicating grave or systematic violations by a State Party of rights set forth in the Convention, the Committee shall invite that State Party to cooperate in the examination of the information and to this end to submit observations with regard to the information concerned.”

In addition a duty to report annually to the United Nations General Assembly on the activities pursuant to a convention has been proposed.

Some comments could be made on the idea of a new monitoring committee on the basis of the functioning of the existing monitoring mechanisms.

The entry into force of the Migrant Worker Convention and the establishment of a new treaty body is rather widely seen as problematic and there is relatively broad recognition of the fact that seven United Nations human rights treaty bodies, all with a reporting procedure and five with one or more complaint procedures is rather too much than too little. There are at least four reasons for the misgivings: The procedural and bureaucratic burden placed on States; the underresourcing of the OHCHR; the varying quality of the treaty bodies themselves and the overlap between the treaty bodies and various procedures of the Commission on Human Rights and its subsidiary bodies.

67 The Bangkok Recommendations, art. 46.
The OHCHR refers in its contribution to the work of the Ad Hoc Committee that in considering the appropriate mechanism which would be entrusted with the task to monitor the implementation of any new instrument, the report of the Secretary-General, “Strengthening of the United Nations: an Agenda for Further Change,” and particularly those parts relating to the human rights treaty body system, should be taken into account. The OHCHR continues that it notes that existing treaty mechanisms and procedures constitute a large, intricate and increasingly complex network, and identifies as a problem the burden of reporting obligations on the resources of States and the Secretariat. The Secretary-General concludes in his report that one effect of all these reporting demands is a failure of States parties to report, either on a timely basis or at all.69

SUMMARY

At this stage it seems evident that a legally binding human rights convention on the promotion and protection of the rights and dignity of persons with disabilities is desired. Political support for such an instrument seems to be almost unanimous. In relation to political goals it might be useful to keep in mind that the original General Assembly resolution states that the mandate of the Ad hoc – committee is to “(...) consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities (...).” 70 However in its recommendations in the report of the 2nd meeting the Ad hoc -committee (...) recommends to the General Assembly that a convention be elaborated and that negotiations thereon be conducted in the Ad Hoc Committee (...). 71 This indicates that the Ad hoc –committee wants to elaborate a human rights instrument called “convention” which indicates that a convention would most likely be similar to the existing human rights conventions.

Raising the question on the mandate of the Ad hoc –committee is not meant to diminish the enthusiasm in the idea of a all-inclusive human rights convention. It is meant to remind that there are also other alternatives to enhance the realization of human rights of persons with disabilities.

68 A/57/387.
69 Office of the High Commissioner for Human Rights (OHCHR) contribution to the work of the Ad Hoc Committee to be submitted to the Secretary-General pursuant to General Assembly resolution 57/229. 2nd session.
In various forums it has been argued that existing human rights conventions have potential in the context of disability. These conventions and substantive rights in them are also applicable to situations of persons with disabilities. Especially the discrimination clauses in the conventions play a critical role and their scope of application should be developed towards a wide understanding of indirect discrimination. This could happen through research and jurisprudence of the monitoring mechanisms of the existing human rights conventions.

In the context of human rights of persons with disabilities the main problem seems to be in the lack of legal remedies. This reflects the long history of considering persons with disabilities as medical entities or as objects of social policy – not as individuals that have rights and are capable of making their own decisions. The problems arising in the lives of persons with disabilities have been considered profoundly as the result of medical pathology of a person – not as problems for the legislator and as failures of the state and municipal entities to undertake positive measures to enhance the situation of persons with disabilities. Therefore solutions to the problems have been other than legal ones.

Because of the emergence of legal understanding of disability it would today seem worth trying to utilize the potential of the existing human rights conventions in the context of disability and this way develop the possibilities of new legal remedies for problems in the lives of persons with disabilities.

Consequently, some type of a new instrument within the mandate of the Ad hoc committee could be developed. However it should be developed taking into consideration also the views that stress more other aspects than a new long list of substantive rights. If a new convention is developed with a list of substantive rights there could be negative consequences.

Firstly many of these rights would most obviously be of such detailed level that practical realization of such rights would be difficult. Secondly, an all-inclusive list of rights in a new instrument would perhaps result in a low number of states that sign the convention.

If an unsuccessful convention is introduced the unwanted effects could be serious. Firstly, a new convention would be incapable in protecting the rights of persons with disabilities on the grounds mentioned above. Secondly, there is a fear that the development of the rights of persons with
disabilities within the existing human rights conventions would be diminished because most of the interest on the subject would concentrate in a new convention.

As a conclusion we could address a few challenges that would be crucial to take into consideration and somehow resolved within the process of considering possibilities for a new convention.

1. Developing the definition of disability / disabled person / person with a disability with emphasis on human rights. This would be a modern alternative to definitions based mostly on the medical condition of an individual. The key issue in this discussion is the notion of participation.

2. Developing the concept of discrimination in the context of disability. A broad and far-reaching concept of discrimination should be examined thoroughly in the context of disability. A new convention would be a good forum to develop the concept of discrimination.

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