## **IDA CRPD Forum**

International Disability Alliance's Forum for the Convention on the Rights of Persons with Disabilities

Contribution to the Office of the United Nations High Commissioner for Human Rights' thematic study to enhance awareness and understanding of the Convention on the Rights of Persons with Disabilities, focusing on legal measures key for the ratification and effective implementation of the Convention

> Geneva September 15<sup>th</sup> 2008

#### INDEX

#### Introduction

- 1. Legal measures for ratification of the CRPD and its Optional Protocol.
- 2. Legal measures for the implementation of the CRPD
  - 2.a. Comprehensive and systematic revision of the national legislation
  - 2.b. Comprehensive disability anti discrimination legislation
  - 2.c. Definition of persons with disabilities
  - 2.d. Legislation on accessibility
  - 2.e. Legal capacity, liberty and related issues
  - 2.f. Access to justice
  - 2.g. Prevention of torture and cruel, inhuman or degrading treatment of persons with disabilities
  - 2.h. Liberty of movement and nationality
  - 2.i. Living independently and being included in the community
  - 2.j. The right to personal mobility
  - 2.k. The right to communication
  - 2.I. Recognition of sign language as an official language in the Constitution and/or special legislation
  - 2.m. Right to Braille as an official script used by blind and deafblind persons
  - 2.n. Education
  - 2.o. Work and employment
  - 2.p. Legislation on international cooperation
  - 2.q. Consultation, coordination and public funding for representative organisations of persons with disabilities
  - 2.r. Indigenous peoples with disabilities
  - 2.s. Psychosocial disability
  - 2.t. Women with disabilities
  - 2.u. Children with disabilities
- 3. Legal measures on national monitoring
- 4. Any other information relating to paragraph 16
  - 4. a. Awareness raising measures

Annex I: IDA CRPD Forum Principles for Implementation of CRPD Article 12 Annex II: Letter of legal experts on article 12

#### Introduction

In response to the request for information of the Office of the United Nations High Commissioner for Human Rights, to support the preparation of the "thematic study to enhance awareness and understanding of the CRPD, focusing on legal measures key for the ratification and effective implementation of the Convention, such as those relating to equality and non discrimination" requested by the Human Rights Council in its Resolution 7/9;

This contribution is submitted by the IDA CRPD Forum following an intensive consultation among its member organisations.

IDA CRPD Forum is a network of representative international, regional and national Organisations of Persons with Disabilities (DPOs) and allied NGOs that accept the DPO leadership.

Its unique composition makes the IDA CRPD Forum the most representative platform of organisations of persons with disabilities, a fact that should be acknowledged by the OHCHR in the process of elaboration of this study, by considering this as the contribution which therefore best provides the agreed and coordinated view of persons with disabilities' organisations in line with article 4 paragraph 3 of the CRPD and within the spirit of "Nothing about us without us".

The steering committee of the IDA CRPD Forum includes the following organisations:

- Disabled People's International (DPI)
- Inclusion International (II)
- International Federation of Hard of Hearing People (IFHOH)
- Rehabilitation International (RI)
- World Blind Union (WBU)
- World Federation of the Deaf (WFD)
- World Federation of the Deafblind (WFDB)
- World Network of Users and Survivors of Psychiatry (WNUSP)
- Arab Organisation of Disabled People (AODP)
- Asia Pacific Disability Forum (APDF)
- European Disability Forum (EDF)
- Red Latinoamericana de Organizaciones no Gubernamentales de Personas con Discapacidad y sus Familias (RIADIS)
- Secretariat of the African Decade
- Handicap Internacional (HI)
- Survivor Corps

### 1. <u>Legal measures for ratification of the CRPD and its</u> <u>Optional Protocol.</u>

The Convention seeks to promote and safeguard the rights of persons with disabilities, and to ensure respect for the dignity, non-discrimination, inclusion and participation on an equal basis with all others in society.

It is urgent for all States Parties that have not yet done so to undertake all necessary legal actions to ensure the swift ratification of the CRPD and the Optional Protocol. In some States this will necessitate legislative amendments prior to ratification (see also section below on measures for implementation), a process in which the active involvement of organisations of persons with disabilities is clearly required as foreseen in article 4 of the CRPD.

Since over one-third of States Parties have not ratified the Optional Protocol, all States must be urged to also ratify this instrument to allow individuals and groups to submit complaints of human rights violations directly to the international committee of experts. Given the lack of or limited capacity of human rights mechanisms in many countries and regions, coupled with inadequate domestic guarantees, international complaints procedures are particularly important to ensure the effective delivery of justice for human rights violations.

• Reservations and Declarations to the treaty

Ratification of both the CRPD and its Optional Protocol, without reservations and/or declarations, demonstrates a State's clear commitment to the universal human rights enshrined in the CRPD. Therefore, States must ratify without reservations and/or declarations. Otherwise, reservations and/or declarations may have the effect – even if unintended - of limiting the application of the Convention and the Protocol, thereby denying persons with disabilities of their full human rights and undermining the universality of these rights.

Although Article 46 of the Convention permits reservations, article 50 of the Convention does not allow for reservations incompatible with the object and purpose of the Convention. Therefore, any reservation or declaration that undermines the principles of the Convention articulated in Article 3 and the purpose as specified in article 1 cannot be allowed. In this case, States Parties to the CRPD must further demonstrate their obligations under the Convention by opposing such reservations.

A legal opinion signed by experts in the field of legal capacity has come to the conclusion that reservations to Article 12 are incompatible with the object and purpose of the CRPD and thus are not permitted under Article 50. The legal opinion is attached as an Annex I to this submission.

It is crucial to note that the UN Human Rights Committee, in the context of the Covenant on Civil and Political Rights, took the view that an unacceptable reservation to the Covenant can be severed from the ratification instrument; in other words, that the reserving State would be fully bound to the Covenant including the provision(s) to which it made a reservation.<sup>1</sup> This issue is still being considered by the International Law Commission and other experts.

Furthermore, allowing broad reservations may in effect discourage governments from making any substantive changes to their existing legislation, thereby nullifying the intended impact of the Convention.

States Parties that have made a reservation or declaration should be encouraged by other States Parties to withdraw them and to clarify their intent to fully comply with the CRPD as adopted.

<sup>&</sup>lt;sup>1</sup> See Report of the Human Rights Committee, GAOR, 50<sup>th</sup> Sess., Supp. No. 40, vol. 1, at 119 (1996).

### 2. <u>Legal measures for the implementation of the CRPD</u>

## 2.a. Comprehensive and systematic revision of the national legislation

In order to implement the CRPD adequately, States Parties will need to undertake, as article 4 clearly states it, a systematic revision of its current legislation in order to align it with the CRPD.

This applies also to those States Parties whose legislation establishes that upon ratification of an international treaty, this treaty becomes part of the national legislation. While in most of these countries the content of the international treaty, once ratified, would supersede any national legislation which is inconsistent with it, this does not replace the need to systematically abolish/amend any legislation, regulation or other norms which are not in line with the CRPD. Neither does it replace the need to in addition legislate laws that make the CRPD operational, in every area covered by the CRPD.

Abolishing or amending laws that are inconsistent with the CRPD includes all legislation that discriminates against persons with disabilities. Mental health legislation would be a good example of this, but also legislation and regulations which regulate access to professional categories and university studies and which often expressly exclude specific disability constituencies.

In countries where the legislation does not recognise the status of an international Treaty, this systematic revision is done before ratification, in others this will most likely be done after ratification. Either way, this process has to start immediately.

In addition, the review of the compatibility of the legislation with the CRPD needs to be ongoing, as often the initial process of harmonisation will not have been done in a thorough enough way.

This systematic revision includes both disability specific legislation as well as non-disability specific legislation which addresses the areas covered by the CRPD. This revision should also ensure that any inadequate terminology referring to persons with disabilities is changed.

Most of the countries have a framework disability legislation which addresses a number of areas covered by the CRPD (education and employment are often to be found in these laws), while other elements covered by the CRPD would be addressed in general legislation (Article 12 would be mostly covered by the Civil laws in many countries, participation in the election process in the general electoral law). The CRPD does not prescribe how such legislation should be divided between disability specific and disability general legislation, but obviously a comprehensive revision of legislation needs to cover both.

Finally, it is important that representative organisations of persons with disabilities are fully involved in this process of legislative reviews and reforms, as it is clearly stated in article 4 paragraph 3.

• Prevention of disability/ "impairment"

In most States, the "prevention of disability" is a fundamental part of national disability legislation, strategies and policies. In some countries, "prevention of disability" covers issues like: health and safety measures at work, traffic accidents, healthy motherhood, drug and alcohol abuse, prevention of violence and even anti-pollution measures.

The deliberate decision to exclude the prevention of disability (the CRPD only refers to prevention of secondary disabilities) from the CRPD should result in the elimination of any reference to prevention of disability from every legislative/policy provision aiming to promote and protect the rights of persons with disabilities. Measures like the ones mentioned in the previous paragraph have no place in the national efforts to promote and ensure the full inclusion and equal participation of persons with disabilities in society.

This is not to say that measures to avoid accidents should not be taken. What we are saying is that these measures should not be part of policies, strategies and laws promoting the rights of persons with disabilities. Those measures should be part of the general public health response for example and moreover, should take into account the rights of persons with disabilities, which would mean at least the following:

- a) Public health campaigns (and other similar campaigns) need to be accessible to persons with disabilities.
- b) Those campaigns should not be defined as prevention of disability, rather as campaigns to avoid accidents at work and traffic accidents, to promote healthy lifestyles, etc..
- c) These campaigns should not "use" the image of persons with disabilities to increase the effectiveness of their message. An unacceptable example would be a campaign promoting road safety, which shows a person who has become a wheelchair user following a car accident.

Moreover, States Parties should ensure that there is no discrimination on the ground of disability in legislation related to abortion and any other biomedical related areas.

# 2.b. Comprehensive disability anti discrimination legislation

The CRPD clearly outlaws any form of discrimination on the ground of disability in any area of life and guarantees equal protection and benefit of the law to all persons with disabilities. In order to ensure effective implementation of the CRPD, this means the adoption of national anti discrimination legislation covering all areas of life, in those countries where such legislation does not yet exist, or its revision, in those countries where it exists.

When doing so, a number of elements are to be taken into account.

i. Discrimination on the basis of disability

Disability anti discrimination legislation needs to protect against all forms of discrimination on the ground of disability.

This should also cover a person who has a disability, even if not legally certified as such according to procedures under national law. The key issue is whether the person has been discriminated or not because of her/his disability.

Moreover, "on the basis of disability" also has to cover other situations of discrimination encountered by: a person who has had a disability in the past, a person who will have a disability in the future or whose genetic information shows that she/he has a higher risk than others to acquire a disability and persons who are associated with a person with a disability.

It is of fundamental importance that national disability anti discrimination legislation specifies all these situations.

#### ii. Protection against all forms of discrimination

Article 5 of the CRPD covers all forms of discrimination

Though not further expounded in the article, it is well known that discrimination comes in different forms: direct, indirect systemic and more. No form of discrimination should be excluded.

States Parties should define the different forms of discrimination and establish their prohibition. In doing so, they should take into account that

- No form of discrimination should be excluded
- The level of protection against any form of discrimination should be the same
- No restrictions or exclusions shall be allowed which in fact would mean discrimination on the ground of disability.

States Parties should also consider including disability-based violence, abuse and exploitation as forms of discrimination, an approach used by the CEDAW Committee in the field of gender-based violence. This should be complementary to any measures taken to implement article 16 of the CRPD.

iii. Denial of reasonable accommodation as a form of discrimination

Article 2 of the CRPD states that the denial of a reasonable accommodation is a form of discrimination. This is a key element of disability anti discrimination legislation. National legislation should clearly reflect this element, removing any doubt that providing reasonable accommodation could be considered a non obligatory measure.

Moreover, it is important that the legislation provides a non exhaustive list of examples of reasonable accommodation, which take into account examples considering people with different types of disability.

#### iv. Accessibility as part of non discrimination legislation

The CRPD makes it clear that lack of accessibility produces human rights violations.

Following many national examples, accessibility legislation has best worked when included in anti discrimination legislation.

In line with article 9 of the CRPD, this will require establishment of non discriminatory accessibility standards and legislation, and the obligation to prevent any new barriers when new infrastructure is being created or current infrastructure refurbished. Legislation should also address making existing infrastructure accessible and establish timelines for preparing access plans and strategies and elimination of existing barriers for all entities that provide services open to the public.

The first step to achieving accessibility is creating systemic accessibility guidelines developed as appropriate to particular contexts (e.g. urban/rural, developing/developed countries). Systemic accessibility promotes individual autonomy and inclusion and participation of persons with disabilities in all activities on an equal basis with others, because there is no need for special negotiations and the provision of the accessibility measure can be automatic.

Individual accommodations are a separate and important element in addition to systemic accessibility in order to address accommodations that need to be tailored to the individual.

For example: In the case of employment, in addition to the need for the premises to be accessible, a specific reasonable accommodation might be required for an individual employee, either in the form of an adaptation to the person's workstation, a change in the working hours or any other form of reasonable accommodation to meet the person's individual needs.

The section on accessibility provides a more detailed description of the elements that are essential to effective accessibility legislation.

#### v. Defining and limiting the concept of disproportionate burden

It is very important that the national disability anti discrimination legislation clearly defines how the concept of disproportionate burden will be applied.

Failing to do so, would limit significantly the obligation of providing reasonable accommodations.

Some of the elements which should be taken into account when defining whether a certain reasonable accommodation implies a disproportionate burden are:

- The size and economic turnover of the organisation obliged to do the accommodation. If the organisation is a branch of a wider organisation, the size of the wider organisation should be the reference.
- The cost/impact of the accommodation
- Whether the accommodation will benefit the organisation generally
- The existence of public (or other) funding which could compensate partly or totally the cost.
- If the infrastructure or service are currently inaccessible in violation of accessibility laws.
- vi. <u>Right of organisations of persons with disabilities to provide legal</u> <u>support</u>

Frequently the violation of the human rights of a person with a disability reflects systemic violation of the rights of a whole community of people with disabilities. In addition, very often persons with disabilities will not have the resources (economic, legal, time availability) to legally pursue situations of discrimination which they have encountered.

Therefore it is vital to enable organisations of persons with disabilities and other human rights organisations to take legal action, subject to the acceptance of the person, in support or on behalf of the person who has been discriminated, in the form of an independent standing in the case. Appropriate cases for class action suit should be established and delineated as well.

#### vii. Enforcement: sanctions and compliance

The real impact of any anti discrimination legislation is usually determined by the existence of effective enforcement mechanisms.

This would include:

- Relevant economic sanctions for the organisation/company that has discriminated on the ground of disability with increased sanctions in case of repetition.
- Permanent or temporary exclusion of organisation/company from public procurement tenders.

It would also be important that Governments provide for the existence of mediation services.

Special treatment should be given in the form of sanctions and remedies against discrimination by government itself and government officials (e.g. in access to justice, discrimination in the form of violence and abuse perpetrated by employees of public institutions, etc.).

#### viii. <u>Protection against retribution or victimisation</u>

It is also important that the national legislation adequately protects victims of discrimination from any action undertaken by the discriminator as a result of the actions undertaking by the victim of discrimination.

#### ix. <u>Reversal of the burden of proof</u>

This is a well established concept in European anti discrimination legislation and is based on the fact that in many situations of discrimination there is a clear imbalance of power between the person who claims to have been discriminated and the discriminator.

The reversal of the burden of proof means that if there is a prima facie evidence provided by the potential victim, it will be then for the perpetrator of discrimination to prove that there has been no discrimination.

#### x. <u>Scope of the legislation</u>

The scope of the legislation should cover all areas foreseen in the CRPD, like

- Education covering all stages of education, from preschool to university education.
- Employment, covering all forms of employment (public, private and not for profit) and all phases (selection, promotion, trade union rights, vocational training).
- Access to goods and services, including the protection against any denial of access/boarding faced by persons with disabilities in restaurants, bars, cinema, transport system and any other facility open to the public.
- Legal capacity and all areas where it is exercised, including free and informed consent in health care decisions and decisions about other services, choice of where and with whom to live, financial and property transactions, voting, marriage and family relations, sexual relationships, law enforcement and penal system.
- Living in the community covering people with all disabilities and all degrees of support needs.
- xi. National anti discrimination implementation body

Experience has shown that effective implementation of national disability antidiscrimination legislation requires the establishment of a national body in charge of implementation of this legislation.

Some of the areas of work of such a body would include:

- Provide legal assistance to persons who have been victims of discrimination on the ground of disability.
- Raise awareness among persons with disabilities on their rights.
- Inform public and private organisations (employers and others) about their legal obligations. This would include, for instance, guidance on the obligation of provision of reasonable accommodation.
- Undertake annual reports on the implementation of the legislation.
- Take legal action (through criminal, civil or administrative law) against violations of legal obligations deriving from equality and non-discrimination.

While in some countries, these bodies could be allocated the role of independent monitoring as foreseen in article 33 of the CRPD, it seems more appropriate to separate both roles, while obviously ensuring that the information obtained by this body is fully taken into account by the institution in charge of undertaking the independent monitoring.

In countries with a broader anti discrimination legislation (not only on the basis of disability) the option of a common body might also be considered. If the body finally established is a more general anti discrimination body (and there are arguments in favour and against of this option), it is vital to ensure that there is adequate knowledge on the specific elements of "discrimination on the basis of disability" in this body.

#### 2.c. Definition of persons with disabilities

States will need to revise their national definition of person with disabilities to take into account the CRPD. When doing so, States need to reflect the social model and the fact that disability has been and continues to be evolving.

No person with a disability should be excluded from the coverage of the CRPD, including also those whose impairment is not visible. This requires that these persons are legally recognised as having a disability.

### 2.d. Legislation on accessibility

Accessibility is a key element of the CRPD and ensures access to and equal opportunities for the realization of other rights, including education, employment and recreation.

Article 9 on Accessibility requires that States Parties take appropriate measures to ensure access to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

Accessibility is a process linking information, transportation, the public domain and built environment. Accessible format information and communications are the essential first step in obtaining details about any service or facility. Transportation and public domains need to provide seamless accessible paths of travel to enable equitable access to the built environment and services.

For accessibility legislation to be effective, the following elements need to be part of it:

- a) Accessibility standards should be mandatory: Either legislated as law, or referred to by the law, and requiring infrastructure, services, communication, etc. to be accessible.
- b) Those aforementioned accessibility standards should be concrete, and translate accessibility into numbers and technical requirements that amount to accessibility (and not, as happens in some countries, talk about 'ramps that make it easy for persons with disabilities to enter buses' etc.).
- c) The government should have a resort to sanctions against those who do not abide by accessibility standards.
- d) Persons with disabilities and organizations should have a resort to civil claims against violation of accessibility requirements.
- e) Accessibility is not only about ramps and elevators. Standards should address accommodations and technical requirements for all types of disabilities, including intellectual disabilities. For example, making services accessible is a very relevant issue for people with intellectual disabilities: how to make the material understood, possible accommodations where waiting on line is involved, training to service personnel in how to respond to their needs, and more.
- f) States should put into immediate effect legislation and standards requiring that new infrastructure, and all services, are accessible.
- g) Legislation and standards must address existing infrastructure as well. Otherwise, with all the infrastructure already in place, no meaningful accessibility will be achieved. In this case gradual implementation is relevant and reasonable timeframes should be legislated for that. Also, a system of balances and exemptions will be more relevant here (rather than in new infrastructure). These should be kept to the narrowest possible, and – once again – should be defined in close consultation with persons with disabilities through their representative organizations.
- Legislation to ensure that information and communication infrastructures and technologies as well as information and materials are universally accessible to persons with different types of disabilities (Braille, large print, plain language, visual information, inductive loop systems, etc..)
- Make accessibility a condition for public procurement and the receipt of public funding. For instance, any organisation providing cultural services (or similar) should only be able to obtain public funding if it is accessible

or in the process of becoming accessible within an established timetable.

 j) Accessibility is also about linguistic accessibility in sign language: professional sign language interpreter services and provision of all information in a sign language and other accessible formats in all media.

### 2.e. Legal Capacity, liberty and related issues

The area most consistently highlighted as requiring legal measures for implementation, including by the High Commissioner for Human Rights, has been legal capacity, governed by CRPD Article 12.

The IDA CRPD Forum has adopted a set of principles on the implementation of Article 12, which are attached as an Annex to this submission, and incorporated by reference.

Article 12 requires reform of the Civil Code (in those countries where it exists) and revision of all areas of law that contain elements of competence and replacement of guardianship and other compulsory interventions with supported decision-making.

Compulsory medical treatment and disability-based detention or institutionalization amount to a limitation of legal capacity (whether or not the mechanism of interdiction or guardianship is used). These practices are also prohibited by Article 14 (liberty) and Articles 17 and 25(d) (respect for physical and mental integrity and free and informed consent in health care).

The CRPD paradigm shift in these areas is fundamental. It means that persons with disabilities can no longer be subject to legal standards or procedures for deprivation of legal capacity, compulsory treatment or forced institutionalization or hospitalization. Instead, such practices must be abolished and replaced with supportive measures that respect the autonomy and integrity of persons with disabilities.

A thorough review must be made to determine the scope of existing law touching on legal capacity, so that all provisions can be revised in compliance with Article 12 and other relevant articles of the CRPD.

In some cases, generally applicable laws may need to be strengthened or reformed to mainstream the concerns of persons with disabilities. Such mainstreaming will benefit all persons while eliminating paternalistic treatment of persons with disabilities.

Application of the CRPD to the penal and law enforcement systems is most closely related with Articles 12 and 14. Legal capacity in the CRPD is not limited to civil matters but comprises all aspects of life. Persons with disabilities, like all others, have duties to other members of society. At the same time, no one must be held responsible for crime unless it is fair to impose blame. Existing legal doctrines wrongly equate blamelessness with certain types of disability and result in greater harm as disability rather than criminal offence becomes the reason for social exclusion and control. This in turn reinforces attitudinal barriers to inclusion of persons with disabilities in communities and the practice of forced institutionalization. Our recommendations include an alternative approach to mainstreaming the rights of persons with disabilities accused and/or convicted of crimes.

We draw attention to the section of this submission on Access to Justice, which is especially relevant to our recommendations regarding the law enforcement and penal systems (as well as generally the exercise of legal capacity by participating in court proceedings).

Please see also the section on the right to communication, which is essential to the expression of a person's will and preferences.

For some persons with disabilities, a gap between ending guardianship and instituting supported decision-making may leave the person in worse circumstances. At the same time, all persons with disabilities have the immediate right to exercise their legal capacity without restrictions. Our recommendations meet both needs, by allowing for partial guardianship to continue only for those persons who do not object to it, for a limited period of time while they are developing support networks.

The following legal measures are necessary for full implementation of Article 12:

- Repeal conflicting laws, such as:
  - Laws declaring the legal incapacity of any group of persons with disabilities.
  - Laws authorizing interdiction or declaration of incapacity.
  - Laws authorizing plenary (full) guardianship.
  - Laws authorizing partial guardianship, unless the following provisions are included:
    - The law only applies to persons who do not object to having a guardian.
    - The law provides for guardianship only as an interim measure, and requires that supported decision-making be developed for each individual.
    - The law will be repealed when there is a comprehensive program to ensure that decision-making support is provided to all those who need it.
  - Laws restricting the exercise of legal capacity based on a test of decision-making abilities, whether generally or in specific areas

such as financial rights and obligations (e.g. disposing of property, entering into a contract, opening a bank account), family rights and obligations (e.g. marriage and parenting), voting or expressing a political or party preference (e.g. in an election, plebiscite or referendum), and decision-making in health and medical context or in relation to housing or services (e.g. whether to undergo a particular treatment or enter a hospital, rehabilitation center or institution).

See also Articles 14, 19, 23, 25(d), 26, 29.

 Laws authorizing compulsory institutionalization, hospitalization or medical or psychological treatment of persons with disabilities (including children with disabilities).

See also Articles 14, 15, 17, 19, 25(d).

 Laws permitting the deprivation of liberty based on perceived danger to self or others (a type of preventive detention), when such laws are only or disproportionately applicable to persons with disabilities.

See also Article 14.

- Adopt or strengthen legislation to the following ends:
  - Legally recognize, promote and provide remedies for the right of persons with disabilities to exercise self-determination in all aspects of life on an equal basis with others. Include the right of children with disabilities to exercise self-determination to the same extent as other children.
  - Ensure that the signatures of persons with disabilities are recognized as valid.
  - Ensure that all forms of communication used by persons with disabilities, including alternative and augmentative communication, are accepted and facilitated in the exercise of legal capacity.

See also Articles 2 and 21.

- Recognize supported decision-making, setting out the legal obligations of supporters and providing for remedies against abuse.
- Establish and adequately fund a comprehensive plan to promote supported decision-making and inform persons with disabilities of their rights, in cooperation with local governments, Disabled People's Organizations (DPOs) and community organizations.
- Define and allocate the proper role of governments, families, communities, DPOs and others in facilitating and providing

decision-making support, providing for a wide range of options to meet diverse needs of persons with disabilities for this type of support. For example, some needs may be met by a personal assistant, others by a trusted friend or family member; community volunteers or paid staff may need to reach out to persons with disabilities who are isolated and may need decision-making support; peer support may meet a variety of needs including decision-making support.

- Ensure that support options address the needs of children with disabilities as well as adults with disabilities.
- Ensure that persons with newly acquired disabilities will have ready access to support.
- Recognize the right to free and informed consent in health and medical context, including medical and scientific experimentation and interventions, and in all services. Take effective measures to penalize violations of this right and provide remedies to victims of violations. Ensure that persons with disabilities have full and equal protection and benefit of these laws and measures. See also Article 25(d).
- Penalize and provide remedies against abuse and exploitation of any person in relation to an exercise of legal capacity, and ensure that persons with disabilities are fully and equally protected. (For example, consumer protection legislation or specific disclosures required for free and informed consent to medical procedures.) Unequal knowledge and/or bargaining power should be taken into consideration.

See especially Article 12.4 and also Article 16.

- Ensure that children with disabilities are required to be registered at birth and recognized as having an equal legal capacity as other children of the same age.
- Address the role of the family in decision-making in a way that respects individual human rights, collective self-determination, and nondiscrimination based on disability. Individual and cultural variations in the definition of family must be respected.
  - Provide for campaigns to raise awareness at the family level of the rights of persons with disabilities to personal autonomy and decision-making.
  - Ensure that persons with disabilities have an equal say in decision-making at the family and community levels.

- Ensure that the right of persons with disabilities to make decisions in any area of life is not conditioned on family approval.
- Undertake a comprehensive review of the penal and law enforcement systems as they relate to legal capacity and persons with disabilities, and institute legal reforms as follows:
  - Abolish the death penalty and other harsh penal measures so that there is no need to claim incapacity-based defenses to avoid serious harm.
    See also Article 17.
  - Abolish the incapacity-based defense of "insanity", which is prejudicial to persons with psychosocial disabilities.
  - Apply existing disability-neutral doctrines such as "mens rea" and "dolo" (relating to the subjective or mental element of a crime) with fairness and sensitivity to the situation of the individual defendant, including his or her disability.
  - Ensure that all persons with disabilities have the right and opportunity to be held innocent until proven guilty beyond a reasonable doubt. See also Article 14.
  - Ensure that acquittal of crimes due to failure to prove a mental element of culpability is treated the same as any other acquittal. See also Article 14.
  - Institute alternatives to incarceration that promote community, taking care to avoid paternalism and coercive social or medical services.

See also Articles 14, 17.

 Modify penal laws and procedures to eliminate discrimination based on race, gender, income, sexual orientation, disability and other factors.
See also Articles 5, 14

See also Articles 5, 14.

 Ensure accessibility of information and communication and of facilities and services throughout the investigative and adjudicatory process (including appeals), and in all detention settings.

See also Articles 9, 14, 21.

• Ensure that persons with disabilities in any form of detention are treated with respect for their physical and mental integrity, and in particular that they retain the right to refuse any medical treatment or experimentation, including psychiatric medications.

See also Articles 14, 15, 17, 25(d).

 Ensure reasonable accommodation for persons with disabilities in detention settings, and provide necessary services, including health and rehabilitation services and supportive services, which should be provided by independent agencies and not by the detaining authority.

See also Article 14.

 Ensure access by persons with disabilities under any form of detention to their families (including chosen families) and support networks.

See also Article 14.

### 2.f. Access to Justice

The inaccessibility of the justice system denies person with disabilities equal protection of the law and equal access to participation in the legal process and its utilization.

#### Physical and communicational access to justice

National legislation should include measures -

- to make physical structures accessible, such as ramps and elevators leading to and within courtrooms, accessible podiums, accessible prisons and detainment centers
- to provide services and means regarding language and communication, such as sign language interpretation, Braille and large print text, augmentative and alternative modes of communication (see definition of "Communication" in Article 2 of the CRPD)
- to provide individual accommodations according to the specific needs of persons with disabilities.

These accommodations are mandated by other articles as well, among them Article 9 on accessibility and Article 21 on Freedom of expression and opinion, and access to information.

#### Procedural and evidentiary access to justice

A central aspect of access to justice expressed in this article, and touching at the heart of access to justice, is the provision of procedural and ageappropriate accommodations in all legal proceedings, in order to enable persons with disabilities to participate fully and equally in the process, whether as complainant, defendant or witness.

#### a) Problem: inaccessibility of procedures

Many legal systems include evidentiary rules that limit or establish as void the capacity of people with disabilities to give testimony.

Even where such procedural barriers do not exist, in most legal systems investigative and judicial procedures whether civil or criminal are not accommodated to meet the needs of persons with disabilities.

The use of formal language and legal terms and the complex formulation of questions do not meet the needs of some persons with disabilities. The system is not adapted to enable communication for people who use alternative forms of communication. It is not adapted to investigate people with difficulties in temporal or spatial orientation arising from their disability, or to properly assess their testimony. The courts do not know to enable these people to testify.

In criminal cases, the police do not know how to question people with such disabilities. In addition, the confrontational circumstances, already intimidating to any person in the process, are doubly so for people with disabilities who may have to confront a defendant who is a family member or serves as a support person.

#### b) Consequences: denial of justice

As a result, evidence is not properly collected and the validity of testimony is challenged by the legal system, barring persons with disabilities from partaking equally in the justice system.

In criminal cases where people with disabilities are victims of crime, abusers easily avoid being charged and brought to trial, resulting in the recurrent closure of cases. Suspects and actual offenders are returned to the streets, perpetuating the vicious circle of violence.

Suspects with disabilities are interrogated without the necessary accommodations; false confessions may be extracted from them as the interrogation is not properly adapted to their cognitive, linguistic or emotional capabilities. The severe outcome can be a wrongful conviction.

#### c) Solution: procedural and age-appropriate accommodations

Article 13 of the CRPD addresses this issue directly, by requiring that the justice system provide procedural and age-appropriate accommodations to ensure accessibility to all.

#### d) The means: legislation

Since procedural accommodations affect evidentiary rules, the means by which to determine them is <u>legislation</u>.

 Abolish laws limiting capacity to testify or otherwise partake in the system Laws which exclude certain groups, on grounds of disability or age, from giving testimony, must be abolished, including laws:

- categorizing the testimony persons with disabilities as null or limited on account of having a disability
- requiring children to be of a certain age as a condition for testifying

Laws excluding persons with disabilities from partaking otherwise in the justice system, for example as lawyers or jurists – must be abolished as well. This step is necessary to enable access to justice, but not sufficient.

#### • Legislate procedural accommodations

Law must be legislated to enable making accommodations to the investigative and testimonial process. Such accommodations will facilitate fair interrogation of persons with disabilities and the possibility for them to tell their stories, serve as witnesses and utilize the justice system on an equal basis with others.

- Examples of procedural and age-appropriate accommodations
- Allowing the person to be accompanied by a chosen support person, who will be present during the investigation or the testimony
- Utilization of special devices and alternative and augmentative communication, such as pictures and communication boards, to enable the person to fully communicate
- Investigations performed by those who have experience and expertise in communicating with persons with disabilities, instead of by a standard police investigator
- Utilization of experts to remove misinformation regarding the disability that may hinder courts from accepting the testimony, assist in understanding the witness' way of communication and ensure that the witness can communicate, understands the questions and is understood during testimony including by assisting in wording the questions
- Formulation of questions in language and style which take into account the evolving capacity of children
- In cases where helpful to the witness and essential to preventing harm or enabling the testimony – giving testimony 'in camera', through video links, in the judge's chambers or outside the courtroom, and giving testimony without official attire (without detracting from the weight and validity of the testimony)
- Sufficient time for giving testimony and appropriate breaks to proceedings
- Provision of information about the proceedings in plain language and childfriendly formats
- Establishing court procedures to enable the process for requesting accommodations.

Providing accommodations should be carried out with discretion: For many persons with disabilities it is important to ensure that testimony is given in the

same way (taking the witness stand, confronting the defendant) and with the same formalities (taking the oath) as the testimony of other witnesses.

## - Accommodations to ensure equal participation in all stages and proceedings

The right to access to justice, and to accommodations where necessary, pertain to people with disabilities who are victims of crime, suspects, defendants, appellants, witnesses, and otherwise party to legal, quasi-legal or administrative proceedings. The justice system should be accessible to all and provide for accommodations relevant for each stage. For example, in many cases persons with disabilities who have been convicted of crime are barred from the possibility available to persons without disabilities, of serving a sentence in community services, and sent to prison instead, on the grounds of inaccessibility of these programs to persons with disabilities. Accommodations would make such programs available to persons with disabilities as well.

#### - Accommodations in response to cross-sectional and disabilitybased violence and abuse

The legal system should provide for accommodations to respond to the intersection of disability and other grounds which result in prevalence of violence and abuse. Examples are gender-based violence; and disability-based forms of violence and abuse, such as institutionalization, forced treatment and restraints.

#### - Age-appropriate accommodations

Research has demonstrated that even very young children, with or without disabilities, can give testimony in court if provided with appropriate information, support and opportunity to demonstrate capacity. Evidentiary laws should both respect the evolving capacity of children, among others to give valid testimony, and address their needs for accommodations related to age, such as specially trained investigators to investigate children, instead of the regular police investigators. These, together with general procedural accommodations, should be in place for children with disabilities.

#### e) Training

Training throughout the justice system as mandated by Article 13, to judges, the State Prosecution, the Public Defense, police and prison staff, and more –is essential to carrying out such accommodations.

## 2.g. Prevention of torture and cruel, inhuman or degrading treatment of persons with disabilities

Article 15 requires effective measures to be taken to prevent torture and other forms of cruel, inhuman or degrading treatment or punishment from being practiced on persons with disabilities.

Such measures include enactment of legislation and development of effective remedies and enforcement measures.

The requirements of Article 16 for prevention of all forms of exploitation, violence and abuse are also relevant. Measures required by Article 16 include independent monitoring of facilities and programs designed to serve persons with disabilities; education of persons with disabilities, their family members and caregivers; availability of services for victimized persons, which must respect autonomy; investigation and, where appropriate, prosecution.

Article 17 requires states to respect the physical and mental integrity of persons with disabilities on an equal basis with others.

In addition to CRPD Articles 15, 16 and 17, states are bound by their treaty obligations under International Covenant on Civil and Political Rights Article 7, the Convention Against Torture, the Optional Protocol to the Convention Against Torture, and regional instruments on the prevention of torture. These obligations, as they relate to persons with disabilities, need to be reviewed and considered in light of the CRPD as a whole. Earlier understandings may not fully reflect the CRPD paradigm shift. For example, monitoring authorities may be relying on the outdated Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care, which was heavily criticized by persons with disabilities and is superseded by the CRPD.

There are two main ways that implementation of CRPD Article 15 needs to be approached: first, by ensuring that the general legislative framework and enforcement measures (including monitoring bodies) for the prevention of torture incorporate persons with disabilities and are accessible and relevant to persons with disabilities who may be victims of torture and ill treatment, for example in the jails and prisons. The second is by incorporating disabilitybased forms of torture and ill treatment in the legislative framework and enforcement measures, including monitoring.

Sites of torture and ill treatment of persons with disabilities that are disabilityrelated (such as psychiatric institutions) have begun to be addressed in human rights monitoring.<sup>2</sup> Some forms of medical treatment have also been found to constitute torture or ill treatment (such as direct electroshock).<sup>3</sup> In addition,

<sup>&</sup>lt;sup>2</sup> See Human Rights Committee General Comment No. 20, see also for example, Association for the Prevention of Torture, Establishment and Designation of National Preventive Mechanisms (2006).

<sup>&</sup>lt;sup>3</sup> European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), The CPT Standards, CPT/Inf/E (2002) 1, p. 49.

experts are beginning to consider forced medical treatment of persons with disabilities as a disability-based form of torture.<sup>4</sup>

These developments should be extended and provided for in legislative frameworks and monitoring mechanisms.

It is important to ensure that disability-based forms of torture are not merely hedged with criteria and procedures for their application, but prohibited by law and effectively prevented. This needs to be highlighted especially with regard to forced medical treatment and institutionalization. An effective framework for the prevention of torture will not be one that permits deprivation of liberty or compulsory medical treatment on the basis of "unsound mind", the "need for care and treatment" or "danger to self of others" of a person with a disability, with or without procedural safeguards. It will instead be one that prohibits these practices and provides persons with disabilities with effective legal remedies to stop their operation and obtain satisfaction and compensation, as well as needed assistance in restoring property and opportunities, support and rehabilitation services desired by the individual and collective measures to ensure non-repetition and social reconciliation.<sup>5</sup>

For example:

- Persons with disabilities should have access to proceedings such as habeas corpus or "amparo" to seek quick release from any form of disability-based detention and to prevent or stop the application of forced medical treatments, whether by state or private entities.
- Persons with disabilities who have been subjected to forced medical treatment, institutionalization, restraints, rape, forced abortion or sterilization, and other kinds of disability-based torture and ill treatment should be legally entitled to assistance in resuming ordinary life, which may include: financial assistance, psychological and/or medical services, peer support, educational opportunities, employment and training opportunities, and housing. These entitlements overlap with rights otherwise guaranteed by the CRPD, but specific programs may be appropriately tailored to persons with disabilities who have experienced torture and ill treatment.
  - Supported decision-making (Article 12) and support services necessary to live in the community (Article 19) are especially relevant here. When CRPD implementation first begins, it should be expected that a large number of persons using supported decision-making and support services to live in the community

<sup>&</sup>lt;sup>4</sup> This was among the subjects discussed in an expert seminar held by the Office of the High

Commissioner for Human Rights on Dec. 11, 2007, on torture and persons with disabilities.

<sup>&</sup>lt;sup>5</sup> See Commission on Human Rights resolution 2002/44, The right to restitution, compensation and rehabilitation for victims of grave violations of human rights and fundamental freedoms.

have been subjected to institutionalization, forced medical treatment and other forms of torture and ill treatment.

- Mechanisms should be established to raise awareness about forms of torture and ill treatment that have targeted persons with disabilities and to honor survivors and victims, respecting the leadership of persons with disabilities in these processes. Some such work has already begun (for example, by the Psychiatric Survivor Archives of Toronto, Canada and others to restore cemeteries on the grounds of psychiatric institutions and tell the stories of those who died there). However, the full value of this work cannot be realized until the torture and ill treatment are abjured and discontinued as a matter of state law and policy.
- International law requires criminalization of torture and other ill treatment. Penal law provisions criminalizing torture and ill treatment should be sure to cover disability-based practices. Persons with disabilities as complainants and witnesses in these proceedings need to be provided with accommodation as required (see section on Article 13, Access to Justice). Such proceedings also need to be conducted with sensitivity and respect for survivors of torture and ill treatment as witnesses and avoid retraumatizing investigative and adjudicative procedures.
- Any laws that have the purpose or effect of authorizing compulsory medical interventions, institutionalization, forced sterilization or abortion, or other forms of torture and ill treatment of purpose with disabilities (such as mental health laws) must be nullified. Other legal provisions that impede the effectiveness of sanctions and remedies against torture and ill treatment of persons with disabilities must also be nullified. For example, ill treatment in the home (including by family members and caregivers) or in a private residential facility must be able to be prosecuted, without impediment by privacy laws.

## 2.h. Liberty of movement and nationality

States Parties have to ensure that legislation related to immigration and asylum does not discriminate directly or indirectly against persons with disabilities.

Moreover, legislation in place (social security or other) shall not discriminate against migrants or refugees with disabilities.

In case of refugees or displaced persons with disabilities, States Parties should:

Make camp infrastructure and all facilities, services, shelter, organizations and information accessible to displaced persons with disabilities. The needs of persons with disabilities should be addressed at the start of the emergency during the site selection, planning and design of camp infrastructure and services, with the participation of persons with disabilities through their representative organisations.

- Promote full and equal access to mainstream services for persons with disabilities (e.g., shelter, water and sanitation, food and nutrition, non food distributions, health services, education, vocational and skills training and adult education, income generation and employment opportunities).
- Provide targeted services, as needed, for persons with disabilities (e.g., specialized health services, support services, physical rehabilitation and prosthetics clinics, assistive devices, nutritionally appropriate food).
- Ensure that displaced persons with disabilities have full access to all durable solution options and to objective information regarding durable solutions in a format that is accessible and easy to understand.

All the above taking into account that needs of persons with disabilities and targeted services for them must respect autonomy, equality and diversity, accessibility and reasonable accommodation as part of non-discrimination and a human rights approach.

# 2.i. Living independently and being included in the community

#### • The right

Article 19 on living independently and being included in the community carries with it legal ramifications for all forms of institutionalization. By stating that living in the community with choices equal to others is "an equal right of all persons with disabilities", the CRPD reaffirms that living in the community is an inalienable right not subject to proving one's 'ability', 'eligibility' or 'entitlement'. In some cases supports may be needed, and the issue then becomes *how* to facilitate living independently and inclusion in the community, as Article 19 indeed spells out.

The most basic rights, such as being given the choice to interact with the community, move freely, make choices about one's own life (such as what to eat, how to furnish one's room, with whom to live, with whom to spend time, where to work, how to spend leisure time) are impossible to uphold in an institutional setting. By definition, an institution is a diversion from the normative way of living in society. It is a system, by essence overriding the personhood and choices of the individuals living within it.

However, it is important to recognize that living independently and being included in the community is not solely a geographical issue, about whether the home is located within or outside a given community. It is a way of life, in which:

- autonomy and self-determination are respected;
- where support is necessary, it is given in a way so as to enhance these;
- and, inclusion in the community is made possible.

#### Legal and legislative implications

#### A. Living in the community and Institutionalization

Thus, this article negates both coerced institutionalization and more subtle forms of institutionalization conducted in various ways:

- posing criteria for eligibility, such as:
  - the level of ability to carry out everyday functions
  - professional determination about 'capability' and 'best interests' of the individual, as grounds for referral to an institution and denying the individual support in the community

- providing state assistance only upon referral to an institution, and withholding it if the choice is made to live in a community setting;

- refraining from creating viable options for living in the community;

- refraining from providing information to persons with disabilities, families and support networks about such an option so an informed decision can be made;

- refraining from providing the means for persons with disabilities to control their lives, make choices for themselves and have them respected as an integral part of their lives.

Article 19 requires the inverse of these:

## 1. Abolish laws and policies subjecting living in the community to threshold criteria

Examples of such laws and policies that should be abolished are those stipulating -

- open-ended categories of circumstances qualifying this right, such as when living in an institution becomes "absolutely necessary", "a measure of last resort", "in the best interests of the person" (the latter especially prevalent with regard to children with disabilities);
- that a person is entitled to state assistance on condition that the person can fulfil everyday tasks without outside support;
- that people with certain physical, intellectual or psychosocial disabilities, or certain degrees of support needs, must live in institutions or are entitled to state support only within institutions;

2. <u>Create laws, policies and programs for viable options for living in the community</u>

Such laws and policies should make available to persons with disabilities "a range of in-home, residential and other community support services" (Article

19(b)). These should reflect "choices equal to others". From this it follows that institutional settings should not be substituted with residential programs for large groups of people, as they do not reflect a way of life acceptable to society as a whole.

Key to enabling the realization of this right is the provision of support services and personal assistance where necessary and chosen by the person. The type of services and manner of their administration should enhance the individual's autonomy, self determination and right to make one's own choices, as well as facilitate inclusion and prevent isolation or segregation from the community, with maximum choice over which services to use and by whom they should be provided.

#### 3. Direct funds towards living settings and services in the community

The shift to living in the community instead of in institutions should be reflected in an increase of government funds allocated toward "in-home, residential and other community support services" programs, compared to funds allocated toward institutional programs.

#### 4. Establish programs to facilitate transition from institutions to in-home settings

Programs should be established to facilitate the transition of persons with disabilities to living arrangements in their communities, including the provision of appropriate support. It is essential to ensure that services in the community are developed and provided simultaneously, so that all individuals previously living in institutions are adequately supported in the community.

Such programs should be developed and carried out in consultation with persons with disabilities through their representative organizations, and should facilitate the individual's right to make choices about one's own life and have them respected.

#### 5. Disseminate information

A major barrier to exercising the choice to live in the community is lack of information. Persons with disabilities, their families and other people in their circles of support are often not aware of the possibility of a life in the community with the necessary and chosen support services, resulting in the absence of *choice* in the matter and in many cases automatic referral to institutions. The possibility of living in the community and the range of services provided should be widely disseminated, with special emphasis on dissemination of information in accessible formats (plain language and other).

#### 6. Phase out institutions

As choices for living in the community increase, programs and support services are developed, budgets appropriately allocated, transition plans carried out, and information and choices made known, the number of people living within institutions will decrease. States should develop programs for closure of institutions, including, as previously stated, concurrent development of services in the community so that no gap exists and individuals previously living in institutions are adequately and immediately supported in the community.

Indeed, a number of countries have closed down all their institutions. Support services can, should be, and in some countries are for a fact provided to enable all persons with disabilities to live in the community.

#### Children with disabilities

The right of children with disabilities to live in the community is especially susceptible to violation, as they are generally not accorded control over where they live. It is imperative to challenge the presumption by both professionals and parents that institutional care can in any way be an appropriate accommodation for children with disabilities. Programs, budget, referrals, and information should all be geared toward enabling children to realize their right to live in the community with their own families, and in cases where that is not possible – to alternative living arrangements within a home and family setting in the community. See further under the chapter "Legislative reform for children with disabilities" below.

#### **B.** Inclusion in the community

Living in the community is also about inclusion in the community, in the sense of not being segregated within the community one lives in, including having:

- a range of accessible and affordable homes to choose to live in;
- the right to make accommodations to turn one's home accessible;
- a non-discriminatory housing process (application, tenants' grievances, eviction, etc.)

National laws and policies should require that a certain percentage of general residential buildings, such as apartment buildings, be constructed so they are accessible, including a percentage of units within.

National laws should enable persons with disabilities to request and make accessibility accommodations related to their life at home, and limit veto by neighbours.

## 2.j. The right to personal mobility

As with other rights in this Convention, the CRPD infuses the traditional meaning of the right to personal mobility with directives that are relevant and pertinent to persons with disabilities.

It is widespread for countries to offer persons with disabilities mobility aids and assistive technologies (wheelchairs, walking aids etc.) as part of a medical framework: The devices are given to persons with disabilities that qualify as

beneficiaries because they are in particular health/medical condition. It can also be a question of enabling access to necessary treatment during travel.

Recognizing personal mobility as a human right necessitates putting an emphasis on the elements that comprise this right: Hence, States Parties should ensure that these devices are put at the disposal of persons with disabilities "in the manner and at the time of their choice", and in a manner that achieve greatest possible independence for persons with disabilities, superseding rules that limit the right to personal mobility

### 2.k. The right to communication.

Persons with disabilities have many different ways of expressing themselves and/or receiving information. CRPD Article 2 does not give a definition of communication. It is an attempt to add all formats, modes and means of communication, persons with disabilities are using, which are usually forgotten and are not written down in national legislations. States or other authorities often forget, for example, to provide information material in Braille, used by blind and deafblind people, on accessible websites or in easy to read formats. In people with disabilities from multi-cultural relation to and ethnic minorities, it is vital to respect cultural norms, values and differences of multi-cultural and ethnic minorities to ensure access to interpreters with the knowledge of the language and lived experience of the culture. The other way around: although the right for persons with disabilities to express themselves is written in article 21, states do not usually have the right persons available to understand all these means and modes of expression.

Education of users of the means and modes of communication, mentioned in article 2, is guaranteed in article 24, but also the education and provision of teachers. Article 9 on giving accessible information and article 26 rehabilitation, for example, provides also the need of other persons, being able to understand persons with disabilities, to be able to communicate them, representing the state or other authorities, professionals in rehabilitation and health settings.

Provisions should be made in national legislation to give persons with disabilities the same rights as others to communicate and to be understood. This should make it possible for persons with disabilities, using the communication, mentioned in article 2, to exercise other human rights, like legal capacity and employment, on an equal basis with others.

# 2. L. Recognition of sign language as an official language in the Constitution and/or special legislation

CRPD is the first international Treaty ever that recognizes sign languages as <u>languages</u> and considers them equal to spoken languages (Article 2).

CRPD guarantees access to services through a professional sign language interpreter service, a right to interact in sign languages, to get information and to express one self in sign language also in official interactions. In addition, CRPD

assures the right to education "in the most appropriate languages" which for Deaf entails bilingual/multilingual approach to learning. All provisions mentioned in Articles 2, 9, 21, 24 and 30 aims at strengthening the status of sign language in different fields of life of Deaf people and thus directly influence their human rights.

CRPD urges State Parties to <u>recognize sign languages and to facilitate the use</u> of sign languages (Article 21). It cannot be highlighted enough that states have to recognize the importance of services, information, education and culture available in sign language in order to assure Deaf people's human rights.

Official recognition of sign languages is itself a very broad concept and it has been implemented in various ways in different states. So far there exist states that have recognized sign languages a) in their Constitution b) in other legislation such as sign language law, education law, parliamentary decisions and discrimination law c) through an official recognition by their government. The recommended way of changing state legislation in order to comply with the CRDP articles related to sign language would be to impose legislation entailing concrete examples (see proposals below).

Some countries have recognised their national sign language within their Constitution in addition to other bills and laws based on non-discrimination of language. Some have created specific sign language laws that recognize sign language as language in its own right giving some governmental support for its use. On the other hand some laws about sign languages are related to disability legislation and are thus based on non-discrimination of disability, i.e. deafness. The right to sign language interpretation services is often implemented through this way. These recognitions can roughly be divided into four categories: constitutional recognition, recognition by specific sign language laws, thirdly recognition through disability laws and finally other legislation. Both general anti-discrimination legislation as well as disability legislation has been used to recognise sign languages and secure human rights of sign language users.

One can conclude that existing ways of recognizing sign languages secure human rights of deaf people through non-discrimination of language, culture and identity of deaf people and deafness per se. CRPD includes both these aspects.

Organizations of deaf people have worked on legal recognition of sign languages and concrete language rights in several specific fields of life, foremost in education. Most of the European states and several non-European countries now have an active sign language policy in which they have granted their national sign language official status in varying degrees. There are a few overviews of existing sign language laws and other legislation that cover areas of early childhood, education (from basic to tertiary education), interpreting services, employment, social and health services, cultural services, media, communication, research, language policy and planning of sign languages.

Core elements in changing the existing legislation or in disposing a new one are **recognition** of sign languages; accepting, facilitating and promoting their **use**;

facilitating their **learning**; and recognition, promotion and support of **cultural** and **linguistic identity**. In addition, right to **accessibility** (sign language interpretation + information in a sign language) must be secured. It is equally important to stress that sign languages **are** treated equally with country's official spoken language/s.

#### A) Accessibility (Article 9.2 (e))

"Professional sign language interpreters" means that states have responsibilities to promote and develop sign language interpreter training, degree and registration as well as to facilitate interpreter services and to promote access to interpreters.

This Article aims at securing freedom of expression and access to information through all forms of communication, including public services in sign language, media and Internet.

#### B) Freedom of expression and opinion, and access to information (Article 21 (b) and 21 (e))

It has been important here to emphasize that sign language is not only a language used by the Deaf in their interaction, but that sign languages should also be approved in official interactions. For example people must have right to submit a document in sign language and to receive a response in sign language, to act and to receive information in court and police, to transact in offices and departments and to get consumer instruction in sign language as well as to receive treatment and other services in sign language.

This item is of great significance and it will have major impact in the future. It means that sign language should be recognized either in legislation and/or in public policies and programs. It also means right for Deaf of all ages to use sign language – children should not be forced to change their language while growing. Promotion also covers support for sign language publications, training, education, research and general usage, i.e. securing the use of sign language to the extent that Deaf people's human rights are realized.

#### C) Education (Article 24.3 (b) and (c))

The usage of sign language must not be prohibited in learning, but this is nevertheless practice in many countries. Deaf community's resources for the benefit of education can be seen as giving adult models (deaf teachers, staff, artists etc) to deaf children. Children can learn how Deaf adults act in the society, student and working life, in advocacy work etc by using different languages, sign language, interpreters and spoken languages in different modes (Deaf people's bilingual or multilingual identity). It is also important to give linguistic roles for children through cultural activities, how Deaf give presentations, i.e. how they use sign languages and other languages in their everyday life. This also supports children to find peers, reference groups and encourages participation in society through means constructed by the Deaf community.

This Article means that education, for example for the Deaf, should be provided in those languages and in such environment that guarantee maximum cognitive and social development. For Deaf people this means sign language/bilingual learning environment. This will set a lot of challenges for teacher training in many countries. Good-quality of sign language skills is a central requirement here as well as Deaf persons' access to teacher training programs. In addition, also other staff members' knowledge on sign language should be increased. Users of sign language need to be entitled to learn their own language as a first language and be taught in this language in order to be part of the society.

#### D) Participation in cultural life, recreation, leisure and sport (Article 30.4)

Cultural materials, Internet and other media, TV programs, movies, theatre, literature and other cultural activities as well as cultural venues, places (such as museums) and information should be provided in accessible formats and in a sign language.

The governments are responsible for establishing and supporting museums of deaf history and research on deaf culture and history, sign language theatre, poetry, song and literature, for people of all ages, in order to support their identity.

- <u>Concrete proposals for Acts of Legislation:</u>
- A starting point for a state is to enact legislation which recognizes the national sign language(s).
- Legally recognize sign language/s as official language/s by granting it/them a special legal status. Thus those sign language/s will be the ones used in legal proceedings, parliament decisions and other administrative acts.
- Set out principles to guide Government in the use of nation's sign language/s.
- Recognize that linguistic rights of deaf people must be guaranteed by several legal measures.
- Legally clarify/state in the legislation that sign language/s of the country is/are the first language/s of deaf people.
- Recognize and secure the right of deaf people to use their sign language and to foster their language and culture.
- Ensure the right for pre school age deaf children to acquire sign language in sign language environments. Adequate provision should be

made to ensure that every person has sufficient access to a language in order for him/her to acquire it in early childhood between birth and the beginning of schooling. This should be facilitated and secured especially for Deaf babies, toddlers and children. Language acquisition should be achieved independently of the fact that a child may be a candidate for Cochlear Implant surgery. That means that visually significant linguistic input (i.e. a natural sign language - and not gestures, mime or a synthetic gestural system) should be offered to every Deaf/hard of hearing infant and child, no matter which technical aids are considered for him/her.

- Ensure that parents, care givers and guardians of deaf children receive education about sign language and its use with their children as early as possible.
- Ensure that laws on day care and preschool education include right of deaf children to have day care and kindergarten education in sign language.
- Ensure that teachers and other workers must have knowledge and high level of sign language skills in their qualifications and training.
- Secure that the quality of bilingual or multilingual education is of high standards.
- Secure that teacher education institutions train professional teachers who know how to teach sign language as mother tongue, first language and second language and who master deaf culture.
- Secure that state provides funds and mechanisms to study learning and teaching in sign language and to produce high level learning material.
- Ensure that national sign languages must be documented (dictionary work) and that sign language research must be done within universities
- Ensure that there exists a Research Institute for sign language enabling research and the preservation of the purity of the Sign Language
- Establish and adequately fund a comprehensive plan to promote awareness of deaf people and hearing people about sign language and linguistic rights of deaf people
- Remove barriers of employment of deaf people and provide enough resources to interpreters specialized in working life.
- Provide sign language interpreter education and set proficiency guidelines.
- Ensure access to sign language interpreter service system and network.

- Promote awareness of employers about sign language, deaf culture and deaf persons in employment.
- Ensure that social and health services are provided in sign language either through sign language skilled experts or sign language interpreter service.
- Ensure that training programs of social and health professionals have enough knowledge about linguistic and cultural needs of deaf people.
- Ensure that state provides funds for translating and producing literature in sign language as well as establishing and maintaining sign language library.
- Recognize the right to have bilingual or multilingual education in sign language learning environment of deaf children, youth and adults.
- Recognize and ensure that sign languages and deaf culture are school subjects and first languages and that they are included in national and school curricula.
- Secure the right to have all kind of information and services in sign language.
- Ensure that public and private broadcasting services provide programs in sign language(s).

# 2.m. Right to Braille as an official script used by blind and deafblind persons.

CRPD is the first international Treaty that recognizes Braille as the script for blind and deafblind persons and considers it equal to other scripts in the world. It is a fundamental human rights to be able express oneself through either a language or via writing, or access information through reading. This is commonly called the right to communication and information.

CRPD assures the right to communication in different formats for different groups who face communication disabilities and in that respect include: (Article 2).

"Communication" includes languages, display of text, <u>Braille, tactile</u> <u>communication, large print, accessible multimedia as well as written, audio,</u> plain-language, <u>human-reader</u> and augmentative and alternative modes, means and formats of communication, including <u>accessible information and</u> <u>communication technology</u>;

In article 9 is the following stated which gives blind and deafblind persons the legal right to access Braille on the same basis as others naturally exercise their right to read and write:

(d) Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;

This gives blind and deafblind persons the right to access all public buildings, institutions and cultural monuments etc, with texts in Braille.

(e) Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;

This means that all elevators, name signs on office doors and bus stops for instance, must have information in Braille or with an audio solutions for blind and deafblind persons.

(f) Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

(g) Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;

This gives blind and deafblind persons the right to use Braille displays to computers so as blind and deafblind persons not only need to listen or to or have it tactile signed, what is on the screen but also read the texts with the fingers. It also provide for the rights to use new technology to produce Braille in an easy and accessible environment for Braille production.

(h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

This means that blind and deafblind persons have the right to access computerised Braille and materials from Braille productions on materials that are requested.

In Article 21 the right to Braille and accessible formats is further stated:

(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;

(c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;

These rights are fundamental rights adjusted in CRPD to also include persons with communication disabilities. This does also means that not only States are
obliged to provide or distribute accessible communication, it takes the issue over to the private sector which also have to provide their information etc, in accessible and usable formats in case their service are directed to the general public.

In article 24 the right to education it states that:

(c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

In this paragraph the CRPD gives blind and deafblind students, in particular children, the right to shoes the best and most appropriate communication forms in their education. This also means that teachers must be educated and specialised in the communication forms he or she shall teach in!

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

It will be a state obligation to make sure that teachers have the right qualification to teach students with different communication disabilities, in order to make sure the education will be provide in the most proper and quality form.

Article 30 gives persons with communication disabilities several rights such as:

(a) Enjoy access to cultural materials in accessible formats;

(b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;

(c) Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

Those paragraphs does not only give blind and deafblind persons the rights to cultural experience in an accessible way, it also challenges the industry to make sure that what is stated in Article 2 on Universal design, be developed and introduced so as blind and deafblind persons can access all these enjoyments.

3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do

not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

This right is extremely important for blind and deafblind persons as copyright exceptions does not always allow for books or magazines etc, to be produced in Braille or in audio. Without strong national laws that permit copyright exceptions for blind and deafblind persons to access all public materials is a fundamental human right strongly stressed in CRPD.

All provisions mentioned in Articles 2, 9, 21, 24 and 30 aim at strengthening the status Braille and other formats for blind persons which directly influence their fundamental freedom and enjoyment of their human rights.

(a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;

Finally it is stated in CRPD that the convention text as such also must be produced in an accessible format for PWD with communication disabilities.

### 2.n. Education

In order to comply with the CRPD state parties will be required to both remove legislative and constitutional barriers to the inclusion of children with disabilities in the education system of the country and implement legislative reform that creates positive commitments to ensure that children with disabilities have access to education and that the supports and adaptations required are made available.

Equality of opportunity for all children with disabilities will also require an end to the system which prevails in many countries, whereby responsibility for the education of children with disabilities falls to ministries of social affairs or health. This serves to exclude children with disabilities from access to the education system. In order to ensure that one Ministry is responsible for the education of all children, legislation should be amended so that The Ministry of Education is responsible for the education of all children.

National legislation and constitutional provisions related to education should recognize and include provisions that explicitly recognize responsibility to provide education to all children within the regular education system including children with disabilities.

#### a) Ensuring access to education

In order to create the overarching framework in which the right to education is assured for children with disabilities, States need to introduce legislation to:

• Ensure a constitutional guarantee of free and compulsory basic education to all children

- Repeal any existing legislation which defines any group of children with disabilities as 'ineducable'
- Ensure that legislation prohibiting discrimination in employment is adopted and enforced. This will enable students with disabilities to become teachers.
- Amend legislation, where necessary to ensure that the Ministry of Education is responsible for the provision of all education
- Establish the right to early identification and assessment to ensure that children with disabilities are able to acquire the educational support and services they need from the earliest possible age
- Require school buildings and materials to be accessible to children with disabilities
- Ensure provision of accessible transport for children with disabilities
- Develop accountability mechanisms needed to monitor school registration and completion by children with disabilities. States should adopt and revise reporting mechanisms to disaggregate data on school participation

#### b) Ensuring quality and inclusive education

In order to promote inclusive quality education for every child, including children with disabilities, legislation will be needed to develop a school system for all. This will require measures to ensure that one school system is responsible for the education of all children. Legislation will be needed to achieve:

- An explicit definition of inclusion in terms of the necessary training, support, policies, resources and facilities to enable children with disabilities to realise an effective education in an inclusive environment
- Allocating financial resources for accommodation and supports of students with disabilities within the education system
- Opportunities for children with disabilities to learn life and social development skills to facilitate full and equal participation in education including:
  - learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills
  - o peer support and mentoring
  - o learning of sign language
- Providing pre-service and in-service training to teachers so that they can respond to diversity in the classroom
- Adaptation of teacher training syllabuses to include inclusive training methodologies
- Revision national curriculum to become accessible to all students and that it be consistent and flexible to all students

- Revision of testing methods to ensure that accommodation is made for students with disabilities
- Inclusion of human rights education within both the taught school curriculum, and the ethos of schools, to promote greater respect for the rights of every child, including children with disabilities
- School buildings and materials that are accessible to children with disabilities
- Ensure that all forms of accessible communication and social development are guaranteed to students with sensory disabilities

# c) Ensuring respect for the rights children with disabilities within education

Children with disabilities often experience physical and humiliating treatment and punishments in schools. The right to education can only be fully realised in children's rights are respected within the school environment. Children cannot learn when they are frightened, bullied, or intimidated. The right to express views and have them taken seriously must also be respected for children with disabilities in the school environment. In order to protect these rights legislation is needed to:

- Prohibit all forms of violence against children in schools, including physical punishment and other inhuman and degrading treatment or punishment
- Require all schools to introduce student bodies, such as school councils, which provide a forum for children to express their views on matters affecting their schooling, and the opportunity to have their views given due weight in accordance with the age and maturity of the children (see also section on Children with disabilities for more detailed

recommendations)

#### d) The right to education of women and girls with disabilities

The education levels and literacy rates of women and girls with disabilities are significantly lower than those of men with disabilities. Girls with disabilities are less often sent to school than boys with disabilities. Girls with disabilities do rarely continue to further education. In order to ensure equality of access to education for women and girls with disabilities, legislation is needed to:

- guarantee gender equality and gender-sensitive education in all educational settings
- take all appropriate measures to eliminate discrimination against women and girls with disabilities in order to ensure to them equal rights with men and boys with disabilities in the field of education and to ensure the same conditions for:

- o career and vocational guidance
- access to studies and for the achievement of diplomas in educational establishments of all categories in rural as well as in urban areas
- ensure equality in pre-school, general, technical, professional and higher technical education, as well as in all types of vocational training and further access to the same curricula, the same examinations, teaching staff with qualifications of the same standard and school premises and equipment of the same quality

(Based on article 10 of CEDAW)

### 2.o. Work and employment

The article 27 of the CRPD foresees a large number of measures to promote the right to work for people with disabilities, thus proving the challenge States Parties face to make this important right a reality in practice.

a) Protection against discrimination

The first key element of the legislation on the employment of persons with disabilities needs to be the protection against any form of discrimination in all forms of employment, for example, public, private and non-profit sectors and in any stage of employment.

Legislation will need to outlaw any discrimination, including harassment, on the ground of disability in all stages of the employment process: selection and recruitment, career development, vocational training provided by the company, salary and social benefits, health and safety at the workplace, trade union rights, continuation in employment.

Legislation that exempts certain employers of persons with disabilities from compliance with any standards generally applicable to employment, such as rights of workers, remedies, or wage requirements, must be repealed.

The denial of reasonable accommodation needs to be defined clearly as a form of discrimination and a non exhaustive list of examples of reasonable accommodation in the workplace should be provided.

Moreover, States Parties should provide financial assistance for those reasonable accommodations that imply a cost, thus reducing situations in which employers can evade their obligations by claiming that the reasonable accommodation imposes an undue or disproportionate burden on them. Also, technical assistance should be provided by public authorities to employers and persons with disabilities on the different types of technical solutions available.

Legislation should establish that the principle of reasonable accommodations applies also in cases where a person acquires a disability while employed: reasonable accommodations to either enable returning to the current position or to be provided with another job of similar category in the same organisation/company.

b) Positive action measures

To fully achieve equality in the access to work and employment, non discrimination measures will not always be enough and need to be complemented with other measures (affirmative action/positive action) which themselves are not considered discriminatory as article 5 paragraph 3 clearly states.

These measures should include:

- financial incentives for employers
- awareness raising measures highlighting the potential of persons with disabilities
- return to work schemes and vocational rehabilitation
- job assistance schemes
- public procurement schemes that give preference to companies which employ at least a certain percentage of persons with disabilities in their workforce and/or exclude companies which have discriminated on the ground of disability.

Measures could also include the use of quotas in the public and private sector. If quota systems are used, these should be designed in such a way that persons with disabilities will have no limitation to their career development once they are in the company/organisation.

c) Mainstreaming

All general measures States Parties use to promote employment need to be accessible for persons with disabilities:

- Technical guidance and vocational and continuing training programmes
- Placement and mediation services
- Self employment and entrepreneurship schemes, co-operatives (micro credits)
- Work experience schemes
- d) Sheltered/supported/special employment

Reference to "all forms of employment" in paragraph 1 a) of article 27 implies that all forms of employment of people with disabilities need to meet the requirements of the CRPD and those that do not so constitute discrimination and should not be accepted.

In a legitimate employment situation, there will be a separation between the role of personnel supporting a person with a disability to perform a job, and the role of supervisor, i.e. rehabilitation counsellors should not be the job supervisors. Persons with disabilities will be recognized as workers and entitled to all the rights pertaining to workers.

As articles 27(e), (f) and (j) state, the aim is to enable employment opportunities either in the open labor market or in self employment, entrepreneurships and independent businesses. Support should be given to enable all those who would benefit from such support to be employed as such with equal rights and benefits, instead of working in sheltered and segregated frameworks – hence the term 'supported employment'.

Careful consideration should be given how to enable persons who would benefit from meaningful work in the open labor market, to do so even if due to their disability they cannot fulfil all the prerequisites of a regular job even though they receive all the necessary and possible support and training. Such working opportunities may be transient – until such persons can be fully accommodated in the workplace and fulfilling the regular prerequisites of the job and in some cases long term – depending on the individual. But in either case the essence of it is that it is conducted as work within the open labor market, and carefully monitored to prevent exploitation.

There are disparate situations that are considered to be "sheltered /supported/special employment"; some of them will amount to discrimination and even forced labour contrary to the CRPD, while others, if they are transitional employment schemes aimed at and resulting in employment in the open labor market, or in essence social enterprises may be legitimate. Care must be taken so that such programs are not a mask for exploitation of people with disabilities doing regular work.

In countries where these forms of employment exist, States should revise the legislation to ensure that forms of employment that do not recognize persons with disabilities as workers, with all the rights pertaining to workers, and supervised as other workers, are no longer licensed to operate; that minimum wage exemptions for certain employers of persons with disabilities are repealed; and that all persons with disabilities who in fact are performing work are provided with all the rights mentioned in article 27, including trade union rights, career advancement, health and safety conditions and prevailing wage standards where these exist.

Persons with disabilities, like other individuals, may desire and benefit from volunteer employment at times. But work, including volunteer work, should be clearly distinguished from rehabilitation. All persons with disabilities performing work that has an economic value or that would be defined as work if another person were doing it, must be considered workers, and have equal rights with other workers.

Volunteer work opportunities should not be promoted for persons with disabilities to any greater extent than for other persons, lest this perpetuate economic inequalities and discrimination in the open labour market.

e) Compatibility between work and disability benefits

In order to avoid penalizing persons with disabilities for being paid for their work, disability benefits and other allowances (like access to healthcare) should be structured in such a way so as not to prevent or discourage persons from seeking employment and work-related income. Benefits and allowances that are disability related and necessary should continue until such time as those benefits and allowances are no longer necessary or are available via the employer.

f) Women with disabilities in work and employment

Ensure through legislation that women with disabilities can enjoy their human right to work. Three quarters of women with disabilities worldwide and up to 100% in some developing countries, are excluded from the workforce.

All appropriate measures should be taken to eliminate discrimination against women with disabilities in the field of employment in order to ensure, on a basis of equality of men and women, the same rights, in particular:

"The right to work as an inalienable right of all human beings, the same employment opportunities, the right to equal remuneration, including benefits, and to equal treatment in respect of work of equal value, as well as equality of treatment in the evaluation of the quality of work; the right to social security, particularly in cases of retirement, unemployment, sickness, invalidity and old age and other incapacity to work, as well as the right to paid leave; the right to protection of health and to safety in working including safeguarding function conditions. the of the of reproduction". Article 11 CEDAW.

Guarantee to women with disabilities that national legislation and general employees' protection laws are implemented. Women with disabilities do also often lack protection from existing trade unions. When women with disabilities become pregnant or during the post-natal period their needs are often not met, which affects them in their equal enjoyment of their rights to work. Article 12 CEDAW.

# 2.p. Legislation on international cooperation

Countries which provide international cooperation should revise their legislation in this area, to ensure that its international cooperation programmes and policies are in compliance with article 32 of the CRPD.

Legislation regulating international cooperation shall ensure that the respect and promotion of the human rights of persons with disabilities is respected in all policies, programmes and projects. This will for instance ensure that all infrastructure development (transport system, education, employment services) takes into account accessibility standards and other measures to ensure that persons with disabilities will benefit from these initiatives.

This also applies to all emergency and humanitarian responses which will need to pay special attention to persons with disabilities, as also article 11 of the CRPD clearly indicates.

The provision of support for capacity building projects, especially those targeted at organisations of persons with disabilities should be explicitly mentioned in the legislation regulating international cooperation and persons with disabilities should be identified as a key target group. Special attention should be put on women with disabilities as they are even more likely to be facing situations of extreme poverty.

Legislation in the donor countries needs to be complemented with legislation in the recipient countries which should also ensure that all projects funded by international development aid (including that coming from multilateral donors) promotes and respects the human rights of persons with disabilities.

If national legislation in this area foresees the establishment of a monitoring structure open to civil society, organisations of persons with disabilities should be explicitly mentioned as being part of these structures.

Persons with disabilities should be included as a key target group in all poverty reduction strategies.

# 2.q. Consultation, coordination and public funding for representative organisations of persons with disabilities.

Articles 4 and 33(3) of the Convention articulate that governments must ensure that the principle of inclusion is respected in the very institutions and mechanisms that are set up to promote and monitor the implementation. Thus, the Convention recognizes the important role that organisations of persons with disabilities will play in implementing the Convention at the national and local levels and further reinforces the principle of "Nothing about us without us".

The way in which the structured consultation, coordination and involvement of organisations of persons with disabilities will vary from country to country, but the adoption of the CRPD should mean a revision of the existing mechanism or the establishment of a new one. When doing so, a number of elements should always be guaranteed:

- There needs to be a coordination mechanism which brings together representative ministries and representative organisations of persons with disabilities and in which the organisations of persons with disabilities need to have a considerable influence.

- The scope of this coordination mechanism needs to be established by legislation which also needs to be produced/revised in consultation with the representative organisations of persons with disabilities.
- The members of such a coordination mechanism should be appointed by the DPOs themselves and not by the Government. All DPOs that meet certain criteria should be included, without a cap on numbers
- Moreover, a wide and open consultation mechanism shall be established allowing other disability organisations to contribute with their views.
- Funding should be made available to representative organisations of persons with disabilities to allow them to undertake advocacy work, an element which already had been foreseen in the UN Standard Rules on the Equalisation of Opportunities of Persons with Disabilities. This funding needs to be provided in such a way that their independence is not restricted.

Moreover, mechanisms should be established that ensure the participation of organisations of persons with disabilities in the development of policies, projects and national anti-poverty programmes, public housing, education, employment and others.

# 2.r. Indigenous Peoples with disabilities and people with disabilities from multi-cultural and ethnic minorities

Preambular paragraph p) outlines the right of inclusion for indigenous persons with disabilities. It states:

"Concerned about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, **indigenous** or social origin, property, birth, age or other status,"

2 General principles

The CRPD introduces general principles which must be applied in the implementation of all other rights and obligations in the Convention. A number of these principles have specific implications for indigenous peoples with disabilities who are recognised as a specific group for inclusion through Preamble p). The CRPD provides the general principles that:

- Introduce a general guarantee of equality and equity for indigenous peoples with disabilities
- Introduce the right of indigenous peoples with disabilities, to have their own autonomy in deciding their own matters of concern to them within a culturally specific framework relevant to them and their needs. Indigenous peoples with disabilities also have a right to their views given due weight in accordance to and equal to the rights of all citizens in their country.

3. Principles of Inclusion and Equality

States Parties when implementing the CRPD and in line with its principles of full inclusion must also ensure that indigenous peoples with disabilities are included equally at all levels of consultation, implementation and monitoring of the Convention without compromising their own cultural identity and integrity in the areas of language, land, family and treaty rights accorded to their non disabled counterparts.

#### 4. Political Inclusion

Indigenous peoples with disabilities must not be denied inclusion in all aspects of political decision making around disability domestically and internationally, and their inclusion is to be guaranteed as a pre-requisite for any representative model within the context of the CRPD.

In relation to people with disabilities from multi-cultural and ethnic minorities, it is vital to respect cultural norms, values and differences of multi-cultural and ethnic minorities.

## 2.s. Psychosocial disability

The preferred terminology of "persons with psychosocial disabilities" should be used wherever relevant in legislation, to refer to persons who may define themselves in various ways: as users or consumers of mental health services; survivors of psychiatry; people who experience mood swings, fear, voices or visions; mad; people experiencing mental health problems, issues or crises. The term "psychosocial disability" is meant to express the following:

- a social rather than medical model of conditions and experiences labeled as "mental illness".
- a recognition that both internal and external factors in a person's life situation can affect a person's need for support or accommodation beyond the ordinary.
- a recognition that punitive, pathologizing and paternalistic responses to a wide range of social, emotional, mental and spiritual conditions and experiences, not necessarily experienced as impairments, are disabling.
- a recognition that forced hospitalization or institutionalization, forced drugging, electroshock and psychosurgery, restraints, straitjackets, isolation, degrading practices such as forced nakedness or wearing of institutional clothing, are forms of violence and discrimination based on disability, and also cause physical and psychic injury resulting in secondary disability.

- inclusion of persons who do not identify as persons with disability but have been treated as such, e.g. by being labeled as mentally ill or with any specific psychiatric diagnosis.

It does not mean:

- an affiliation with psychosocial rehabilitation.
- acceptance of any label that an individual may not identify with.
- a category to be used in addition to "mental illness" or "mental disorder".
- a belief in psychosocial "impairment".

CRPD Article 1 refers to

"those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

In this context, the reference to persons with "mental" impairments includes persons with psychosocial disabilities. However, for the reasons given above, national legislation implementing the CRPD should use the preferred terminology of "persons with psychosocial disabilities," which is in keeping with the social model of disability reflected throughout the CRPD, and the recognition that disability is an evolving concept as provided in CRPD preambular paragraph (e).

Given the fact that persons with psychosocial disabilities are included under CRPD Article 1, a provision that is linked to the purpose of the Convention and thus not subject to reservations of any kind, all legislation applicable generally to persons with disabilities must include this group, including anti-discrimination legislation (including reasonable accommodation); eligibility for subsidies, programs and services; and recognition of organizations of persons with disabilities for consultation purposes as required by CRPD Article 4.3.

### 2.t. Women with disabilities

Article 6 in CRPD on women with disabilities; recognize that women and girls with disabilities are subject to multiple discrimination. In this regard national legislation shall ensure the full and equal enjoyment of all human rights and fundamental freedoms in the political, civil, economic, social, cultural or any other field, set out in CRPD and in line of the Convention on the Elimination of All Forms of Discrimination against Women, CEDAW.

Prohibition of discrimination shall mean any distinction, exclusion or restriction made on the basis of gender or disability, which has the effect or purpose of impairing or nullifying the recognition and enjoyment by women, on a basis of equality between men and women of human rights and fundamental freedoms. (CEDAW)

National legislation shall prohibit any act or practice of discrimination against girls and women with disabilities and ensure that public authorities and institutions shall act in conformity with this obligation. (Articles 3 and 4 of the CRPD).

# Further ensure that national legislative measures are undertaken to address girls and women with disabilities and:

Guarantee the full development, advancement and empowerment in all spheres of life. (Article 6)

Ensure the protection against all forms of discrimination on the basis of ethnicity, age, religion, language, political or other opinion, national, indigenous or social origin, property, birth, or any other ground of discrimination set out in CRPD and other UN treaties.

Guarantee through legislation, due to less involvements of girls and women with disabilities in many areas, access to the civil, political, physical, social, economic and cultural environment, to health and rehabilitation, to employment and vocational training, to free and compulsory primary and secondary education and to useable information and communication in accessible modes, means, formats and language, as set out in CRPD. (Articles 2, 21 24).

Through law and other appropriate means, embody the principle of the equality of men and women in national constitutions or other appropriate legislation and to ensure that the practical realization of this principle also embraces women with disabilities. (Preamble n), article 2 and CEDAW)

Ensure that revision of national legislation that target women in general also takes into account women with disabilities. (Article 4 paragraph c of the CRPD)

Respect of the inherent dignity of girls and women with disabilities, the individual autonomy and the freedom to make own choices, the independence of the person, including free and informed consent in all matters related to decisions directed to women with disabilities. (Articles 3, 12, 24, 25 and 26 of the CRPD).

Ensure that legislative and administrative measures include assistance and support services and cover all stages of life. (Preamble x), articles 4, 7, 9, 16, 19, 20 of the CRPD).

Ensure that appropriate legislative, administrative, social, educational and other measures are undertaken, to protect women with disabilities, both within and outside the home, from all forms of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation. (Preamble q), article 12, 16, 23 of the CRPD).

Guarantee that effective women- and child-focused legislation and policies, are put in place to ensure that instances of exploitation, violence and abuse against

women and girls with disabilities are identified, investigated and, where appropriate, prosecuted. (Article 12, 16 of CRPD).

All appropriate legislation measures and investigations are taken, to prevent all forms of exploitation, violence and abuse, including psychological violence, in families and by caregivers or by any other person. (CEDAW, article 12, 16).

Ensure that legislation of protection on violence, exploitation and abuse and related services are age-, gender- and disability-sensitive. (Article 16 of CRPD)

Take all appropriate legislative measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of girls and women with disabilities who have become victims of any form of exploitation, violence or abuse. Such recovery, reintegration and protection services shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person, be of free informed consent and takes into account gender- and age-specific needs. (Articles 16, 25 of CRPD and CEDAW)

Ensure that Girls and Women with disabilities have access to quality health services that are gender-sensitive and include health-related rehabilitation. (Articles 25, 26 of CRPD).

Ensure to women with disabilities appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.(CEDAW)

Ensure appropriate assistance to women (and men) with disabilities in the performance of their child-rearing responsibilities (Article 23)

Ensure that women with disabilities have the right to family benefits, bank loans, mortgages and other forms of financial credit. The right to participate in recreational activities, sports and all aspects of cultural life. (Articles 13 of CEDAW and 30 of CRPD)

# National policies and programs include Girls and Women with disabilities and ensure that:

A gender perspective is incorporated in all national programs and policies directed to PWD to promote the full enjoyment of human rights and fundamental freedoms by both women and men, girls and boys with disabilities. (Preamble s), article 3, 4).

Special measures and programs are developed to protect girls and women with disabilities during situations of natural disasters, armed conflicts and occupations. (Preamble u), article 11).

The knowledge of the living conditions of women with disabilities and that the majority of them live in poverty and in this regard, recognizing the critical need to address the negative impact of poverty on girls and women with disabilities. (Preamble m), article 28 of the CRPD, Millenium Development Goals

Girls and women with disabilities of all ages, have access to social protection programmes and poverty reduction programmes.

The judges, the prosecutor, police, health professionals and other civil servants are familiar to girls and women with disabilities and their vulnerable situation in cases of domestic exploitation and violence. (Article 13 of CRPD and CEDAW).

Through information and education to health staff, police and others, on how to avoid, recognize and report instances of exploitation, violence and abuse of Girls and Women with Disabilities. (Articles 4, 13, 20, 26 of CRPD and CEDAW).

Women with disabilities have full access to a safe place (sheltered refuge), which meets all physical, social and emotional needs in cases of domestic violence. (Article 4, 9, 16)

Girls and women with disabilities have the opportunity to be actively involved in decision-making processes, policies and programmes, including those that directly concerning them. (Preamble o), article 3, 4, CRC and CEDAW).

Women with disabilities have the opportunity to participate in and benefit from rural development programs and policies. (Article 9, 25, 26, and CEDAW)

# 2.u. Children with disabilities

#### 1 General principles

The CRPD introduces general principles which must be applied in the implementation of all other rights and obligations in Convention. A number of these principles have specific implications for children with disabilities and will require the following legislative action:

- A general guarantee of equality for children with disabilities
- A requirement that in all actions concerning children (including children with disabilities), whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration
- Introduction of the right of children with disabilities, to express their views on all matters of concern to them and to have their views given due weight on an equal basis with other children, and in accordance with age and maturity, in all settings (for example, family, schools, health care, courts, and all relevant administrative proceedings)<sup>[1]</sup>. Disability and ageappropriate assistance must be provided to ensure the realisation of this right.

### 2 Protection from violence and abuse

Children with disabilities are disproportionately vulnerable to physical, psychological and sexual violence. In addition, in many countries, girls with disabilities are forcibly sterilized, and subjected to highly invasive and often risky procedures in order, for example, to avoid the 'inconvenience' of menstruation, or as a form of child protection – if the child is raped, at least she will not have a baby. Children are being drugged for behavioral and emotional reasons at increasingly early ages, including infancy. They are powerless to defend themselves or even to understand what is being done to them, and a generation is growing up without knowing what their minds are like free of chemical alteration. However, in many if not most countries, neither the mainstream criminal justice systems, nor specific child protection legislation is sufficiently sensitive to, accessible and appropriate to identify and protect children with disabilities from violence. Existing child protection legislation needs to be reviewed to bring in line with the CRPD and in particular, specific legislative measures must be introduced to ensure that for children with disabilities, there are mechanisms in place to prevent violence, support and rehabilitate those children who do experience violence and to identify, investigate and prosecute perpetrators of violence. This will include the following:

- Repeal of legislation which provides justifications for violence against children including as a form of 'control or 'discipline' such as 'reasonable chastisement' or 'lawful correction' in any setting including the home, schools, institutions and the juvenile justice system (not only are these defences widely afforded to parents in many countries, but institutions for children with disabilities are also known to defend their use of corporal punishment of children with disabilities as necessary for their education and discipline)
- Prohibition of all forms of violence against children, including all corporal punishment, sexual violence, and torture and other cruel, inhuman or degrading treatment or punishment, such as, for example, the use of drugs to control behaviour or emotions, in all settings, including the home, schools, institutions and the juvenile justice system
- Comprehensive and inclusive child protection framework which gives explicit recognition to the rights of children with disabilities to protection from all forms of violence
- Mechanisms to ensure that all facilities and programmes for children with disabilities are subject to appropriate standards, and are monitored effectively by independent authorities. Children themselves must have entitlement to confidential and supported access such monitoring bodies
- Effective and accessible complaints mechanisms and remedies for children with disabilities when their rights are violated, including in the courts, with provision of age and disability appropriate support

• Prohibition on the use of sterilization of children with disabilities for social and psychological reasons.

#### 3 Family life and care of children with disabilities

The right to family life is at particular risk to children with disabilities where there is a lack of understanding about the nature of disability, where there are no community based services to support families in their day-to-day care of children or where families are too poor to bear the costs associated with caring for a child with a disability. Accordingly, emphasis must be on the provision of the necessary supports to families to enable them to care for their children. The CRPD also makes explicit that where families are unable to care for a child with a disability, any alternative placement must be within the wider family or within the community in a family setting. Institutional care is not acceptable. The key legislative actions needed to protect the right to family life include:

- Provisions which affirm that **c**hildren with disabilities have equal rights to family life, and must not be separated from parents against their will unless necessary for their best interests. In addition, a child must never be separated from parents because the parent or the child has a disability.
- A prohibition on the institutionalisation or detention of children on the grounds of disability
- Inclusive children's legislation, which places an obligation on the relevant authorities to:
  - provide community based support to enable children with disabilities to remain with their families (for example, information, awareness-raising, inclusive pre-school and day care services, respite care, laundry delivery, transport services)
  - develop time limited plans to end the placement of children with disabilities in institutions and promote and support the development of family-based care within local communities for children unable to live with their own families (for example foster parents, small group homes)
- An obligation to ensure regular review of placement of children, including children with disabilities, in any settings away from home, and to respect to the right of children to be heard in any review procedures. They must be provided with the appropriate support and assistance to enable them to access such procedures
- Entitlement to social protection programmes for families with a child with a disability (for example, child benefits, disability allowances, caring allowances, mobility allowances)
- Universal requirement to register every birth
- 4 Right to life

Children, including babies, with disabilities are often allowed to die on the basis that their quality of life does not justify intervention, or that it is in their best interests. Such practices violate the right to life and discriminate against children with disabilities. These practices are discriminatory, and the following legislation will be necessary to protect against their continuation:

- Explicit provisions to affirm the right to life of a baby or child with a disability on an equal basis with others
- Introduction of appropriate punishment for all those that directly or indirectly violate the right to life, survival and development of children with disabilities

#### 5 **Promoting and monitoring implementation**

Implementation of the CRPD in respect of children needs to be undertaken in line with the comprehensive provisions of the CRC. In addition, children with disabilities need direct access to mechanisms for both promoting and monitoring implementation of the CRPD. It is not sufficient to assume that adults with disabilities can adequately represent their concerns, experiences and perspectives. They need to be consulted directly, through their own NGOs, when these exist, or through NGOs and DPOs that involve children in a meaningful way, in both the development of relevant legislation and policies, and in the subsequent monitoring of implementation. Their entitlement to such involvement needs to be established through legislation in order that government can be held accountable on its obligations to children with disabilities. Equally, any human rights institution needs to ensure that it directly represents the views and concerns of children with disabilities. Accordingly, the following legislative action will be needed:

- Review of all legislation affecting children to ensure compliance with the provisions of both the CRPD and CRC, and the explicit inclusion of children with disabilities where appropriate
- Introduction of provisions to require governments to consult with, and actively involve children with disabilities, through their representative organisations, when developing and implementing relevant legislation and policies and in monitoring that implementation
- Establishment of a human rights commission or children rights commissioner with an explicit obligation to promote and protect the rights of children with disabilities

# 3. Legal measures on national monitoring

The UN Convention on the Rights of Persons with Disabilities represents a significant step forward in the recognition of the essential rights of persons with disabilities. However, national monitoring is key to making the principles of the Convention a reality.

Article 33 looks for states to ensure that a framework is in place to "promote, protect, and monitor" the Convention's implementation. This framework should be independent from the government to promote full transparency.

Moreover, the framework should be in line with the principles relating to the status and functioning of national institutions for protection and promotion of human rights (the Paris Principles) and should, as stated in paragraph 3 of article 33, ensure the involvement and full participation in its work of organisations of persons with disabilities.

In this regard, governments in consultation with representative organizations of persons with disabilities must assess their existing National Human Rights Institutions (NHRIs) to evaluate whether this mechanism complies with Article 33 of the Convention. Most likely, NHRIs will lack the disability specific expertise and their work will only be effective if additional resources (financial and human) are allocated to the existing NHRI. It must be ensured that the staff of the national monitoring framework is familiar with the provisions of the CRPD and understands the vital role organisations of persons with disabilities.

In countries which lack NHRIs or in which the existing NHRIs is not adequate for the monitoring of the CRPD, States will need to establish a new monitoring framework which would be specific for the monitoring of the implementation of the CRPD.

On the basis of the Paris Principles, the role of the national monitoring mechanism should include:

- Monitor the implementation of the Convention and report annually;
- Report and make recommendations to the Government, at own initiative or not, on human rights matters related to persons with disabilities and initiative to promote the human rights of persons with disabilities;
- Promote harmonization of national law with the provisions of the CRPD;
- Contribute to the report of the State to the CRPD Treaty monitoring body;
- Have the possibility to submit its own report to the CRPD Treaty monitoring body;
- Cooperate with regional and United Nations human rights bodies;
- Assist in the formulation of education programmes on the human rights of persons with disabilities;
- Raise public awareness about the human rights of persons with

disabilities and efforts to combat discrimination on the ground of disability;

The involvement of the representative organisations of persons with disabilities in the work of the national monitoring framework needs to be clearly established and meet the criteria established in paragraph 3 of article 33.

Currently the majority of the and statistics vast data available are not based on the necessity of monitoring the norms of the UN Convention (see Art.31), in particular the necessity "to identify and address the barriers faced by persons with disabilities in exercising their rights". In fact, comparative data on discrimination and the absence of equal (health. opportunities to enjoy rights and fundamental freedoms education, work, etc.) is lacking in all the countries in the world.

Furthermore, in order to promote equality and eliminate discrimination on all grounds in accordance with article 5 of the CRPD, it is very important that the information collected in accordance with article 31.2, be disaggregated by gender, age and additional grounds, and used to help assess the implementation, and to identify and address the barriers faced by girls, boys, women and men with disabilities in exercising their rights.

## 4. Any other information relating to paragraph 16

Article 8 of the CDPD establishes clear obligations on States Parties to do their utmost to make the content of the CRPD known to all relevant stakeholders, including persons with disabilities and their organisations. Awareness raising should be both targeting general society as well as specific groups in society.

#### 4. a. Awareness raising actions should include:

Provide the text of the CRPD and the legislation which results from its implementation in the different official languages of the State Party as well as in accessible formats.

To ensure that the laws and all other resolutions and regulations, and especially those that affect persons with disabilities, are published in accessible formats and a wide distribution is done among entities, State organs, organisations of persons with disabilities, families and persons with disabilities.

Ensure through training that the judges, the prosecutor, police and other civil servants working in the area of justice know and apply the rights enshrined in the CRPD.

Ensure that persons with disabilities and their organisations and disability related entities take part in the development and implementation of campaigns, permanent and systematic, of awareness raising and sensitisation of society.

Jointly with media, organisations of persons with disabilities and related public authorities, to develop a guide and norms for the dissemination of disability related information.

States Parties should introduce the principles of universal design into the curricula of all occupations working on the built environment, which takes a pro-active approach by recommending the principles into the incorporation of universal design curricula of architects, engineers and town planners, and, by and large, into the training of all vocations working on the built environment.

Ensure that vocational training in general, and especially that linked to disability (medicine, Psychology, law, teaching, etc...) incorporates the rights-based approach to persons with disabilities.

Ensure resources and strategies for the capacity building of public officials, civil servants and service providers, working in legislative, executive and judiciary so that persons with disabilities are taken into account in line with the CRPD.

Encourage employers to hire individuals with disabilities/ensuring that employers do not discriminate due to a disability

Promote communal and recreational activities for persons with disabilities.

#### Annex I

#### **IDA CRPD Forum**

#### Principles for Implementation of CRPD Article 12

#### Introduction

Article 12 accords to people with disabilities recognition equal to others as full persons before the law. To be recognized as a full person before the law means that one's legal capacity, including the capacity to act, is equally recognized. Article 12 also imposes a positive duty on the state to establish support measures to ensure that the barriers to exercising legal capacity are removed and that the supports are in place for people with disabilities to fully enjoy and exercise this capacity. Insofar as present day national laws impose barriers to the exercise of legal capacity by persons with disabilities, or deny access to needed supports for the exercise of legal capacity, it is necessary for States in accordance with their obligation under article 4 (1) (b) to modify these laws to bring them in consonance with article 12. In order to assist States Parties in their law reform activity we have outlined the implications of article 12 below.

#### **Overarching Principles**

- 1. "Legal capacity" is best translated as the "capacity for rights and capacity to act".
- 2. "Legal capacity" for the purpose of the Convention on the Rights of Persons with Disabilities means both the capacity for rights and the capacity to act. This applies in the legal systems of all countries for all people, including those with disabilities.
- 3. The right to enjoy and exercise legal capacity applies equally to all people, including those with disabilities, irrespective of the nature or effects of their disability or apparent need for support. Legal capacity cannot be questioned or challenged based on disability.
- 4. People with disabilities who need support to exercise legal capacity have a right to be provided with such support. Support means the development of a relation and ways of working together, to make it possible for a person to express him or herself and communicate his or her wishes, under an agreement of trust and respect reflecting the person's wishes.
- 5. All people who have difficulty exercising their legal capacity can be accommodated within the support paradigm.
- 6. All adults, including those with disabilities, have an inalienable right to exercise their legal capacity. This means they cannot be prevented from doing something that they are otherwise permitted to do in the exercise of

personal autonomy. They also have the corresponding duty to fulfill their responsibilities. Support and/or reasonable accommodation may be necessary to equalize the effective enjoyment of these rights and fulfillment of duties.

- 7. All children, including those with disabilities, have an evolving legal capacity, which at birth, begins with full capacity for rights, and evolves into full capacity to act in adulthood. Children with disabilities have the right to have their capacity recognized to the same extent as other children of the same age, and to be provided with age- and disability-appropriate supports to exercise their evolving legal capacity.
- 8. Parents and guardians have the right and responsibility to act in the best interests of their children while respecting the child's evolving legal capacity, and the state must intervene to protect the legal capacity and rights of children with disabilities if the parents do not do so, in accordance with the Convention on the Rights of the Child. The parents' or guardians' rights to act on behalf of their children cease when the child reaches the legal adult age. This must be the same for all persons to avoid classifying people with disabilities as children at an older age than others.

# Building Legislative and Community Structures for Supported Decision Making

- Governments are responsible for replacing existing substitute decision making laws and policies with supported decision making mechanisms that are recognized in legislation and have corresponding policies and programmes to effectively implement a system of supported decision making.
- 10. Governments are responsible for developing, supporting, promoting and offering support services, and for establishing safeguards to ensure a high quality of support and its compliance with standards such as: respect for the rights, will and preferences of the person, freedom from conflict of interest and undue influence, and being tailored to individual circumstances.
- 11. Support must not restrict the rights of the person or coerce the person to act in a particular way. Support must not affect his or her capacity to act. A person cannot be made to accept support against his or her will.
- 12. Different types of support should be promoted and encouraged to meet the wide range of needs among people with disabilities and allow for personal choice among different options. Types of support may include, for example, support networks, personal ombudsperson, community services, peer support, personal assistant, and advance planning. Age, gender, cultural and religious preferences, and similar factors must be taken into account, as well as needs expressed by people with different types of disabilities.
- 13. Interim measures may be needed when it is difficult to determine a person's wishes and it appears that the person may need support, or when support

fails despite good efforts. In such cases, skilled supporters trained in establishing proper communication and the obligation to respect autonomy should be available to help. Governments should also promote advance planning for support that people may anticipate needing in the future.

- 14. A person may agree with his or her supporter(s) that the supporter(s) can make certain types of decisions, should the supporter be unable to determine the person's wishes at a particular time. This does not mean that the person loses his or her right to make those decisions. The supporter is bound to keep making the effort to communicate and to follow the person's wishes as far as they may be known.
- 15. If no such authorization has been made and communication has failed despite good efforts, skilled supporters should continue trying to establish communication, while a decision is made that has the least possible effect in foreclosing opportunities for later revision.
- 16. Decisions that involve highly personal values and/or controversial measures that may violate a person's physical or mental integrity such as sterilization, cochlear implants, neuroleptic drugs, electroshock and psychosurgery, should not be permitted without the informed and affirmative consent of the person concerned.

#### **Dismantling Substitute Decision Making Systems**

#### 17. Governments must act immediately to

a. recognize the equal rights of all persons to have and exercise legal capacity without discrimination based on disability;

- b. establish a legislative, policy and financing basis for
  - *i.* provision of support in decision making in accordance with the principles outlined above; and
  - *ii. the duty of all those in the public and private sectors to accommodate persons with disabilities who may require support in decision making; and*

#### c. abolish

- *i. plenary guardianship;*
- ii. unlimited time-frames for exercise of guardianship;
- *iii.* the legal status of guardianship as permitting any person to override the decisions of another;
- *iv.* any individual guardianship arrangement upon a person's request to be released from it;
- v. any substituted decision-making mechanism that overrides a person's own will, whether it is concerned with a single decision or a long-term arrangement; and
- vi. any other substituted decision-making mechanisms, unless the person does not object, and there is a concomitant requirement to establish supports in a person's life so they can eventually exercise full legal capacity.

18. All laws and mechanisms by which a person's capacity to act can be

deprived or restricted, based on differences in capabilities, must be abolished or replaced with laws that recognize the right to enjoy and exercise legal capacity. In addition to substituted decision-making mechanisms as mentioned above, this includes declarations of incapacity, interdiction, welfare orders, commitment to institutions, and compulsory hospitalization or medical treatment.

- 19. Similarly, any laws disqualifying a person from enjoying rights or performing legal acts or responsibilities based on disability must be abolished. For example, voting, holding public office, serving on juries, giving or refusing free and informed consent, inheriting or owning property, marriage and raising children, are rights guaranteed in the Convention that also involve an exercise of legal capacity. Support and/or appropriate accommodation must be provided where necessary to exercise these rights and responsibilities. The signatures of people with disabilities are entitled to equal recognition as those of others.
- 20. In implementing Article 12, governments must address its implications for criminal responsibility and the criminal justice system. Persons with psychosocial disabilities have an equal legal capacity with others to be held responsible for wrongdoing, whether through a civil, criminal or other process, and to be provided with all needed supports and accommodations to ensure access to justice and conditions of punishment that respect human rights and dignity. The death penalty and similar harsh measures must be abolished to ensure humane treatment for all.
- 21. Implementation of all aspects of Article 12, including the development and provision of support, needs the active involvement and partnership of people with disabilities and the organizations they choose to represent their interests (in particular, organizations of people with disabilities controlled by themselves). All those who seek the protection of the Convention within an evolving concept of disability should be welcomed.

#### Annex II

#### Legal Opinion on Article 12 of CRPD

Several questions are raised around Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD). Some of these questions which are common across jurisdictions and have been raised in different parts of the world are as follows: how has legal capacity been constructed in the CRPD? Does it include both the capacity to have rights and the capacity to act? If yes then has this legal capacity been extended to all persons with disabilities or have certain persons been excluded? If not, will it be permissible for a State to enter reservations on those parts of the article which guarantee universal legal capacity?

In order to facilitate State understanding of their obligations under the CRPD generally and article 12 more particularly we are setting down the following legal opinion.

#### **Construction of Legal Capacity**

Legal capacity consists of two integral components: the capacity to hold a right and the capacity to act and exercise the right, including legal capacity to sue, based on such rights. Both these elements are integral to the concept of legal capacity hence recognition to the legal capacity of any group or individual mandates recognition of both these elements. It has been found that denial of legal capacity to any individual or group has also meant negation of both the right to personhood and the capacity to act. On the study of municipal legislations, it has also been found that whenever such discriminatory laws have been challenged, they have been at first replaced by legislations which accord symbolic recognition to the rights of the excluded group, thus whilst the capacity to hold rights is recognized, the capacity to exercise those rights continues to be denied. In comparison international human rights law, which has often been adopted to counter discriminatory municipal legislations, constructs legal capacity to include both the elements of identity and agency. Article 15 of the Convention on the Elimination of Discrimination of Women is a case in point.

Article 1 of the UN Convention on the Rights of Persons with Disabilities states that the purpose of the Convention is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities ......" This purpose has to be furthered by all the provisions of the CRPD including the article on legal capacity. And the text of article 12 would need to be read informed by this objective.

#### **Identity and Agency**

By paragraph (1) of Article 12 State Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law. This paragraph of article 12 addresses the identity requirement of legal capacity and recognizes the personhood of persons with disabilities.

Paragraph 2 of article 12 provides that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." A non-disabled citizen who owns real estate, or a car, a horse or a book is entitled to sell the house, to hire the car, gift the horse or lend the book. All these and similar dispositions as an owner are a part of his or her legal capacity. Paragraph (2) by extending the same rights to persons with disabilities fulfils the agency requirement of legal capacity. The non negotiable nature of this commitment is evidenced by the inclusion of individual autonomy, non discrimination and equality of opportunity in the list of General Principles which the States both refrain from actions that undermine the principles and initiate efforts which would promote them.

That paragraph (2) of article 12 provides for the agency requirement of legal capacity is further borne out by the remaining paragraphs of article 12. Thus

paragraph (3) of art 12 requires States Parties to "take appropriate measure to provide access by persons with disabilities to the support they may require in exercising their legal capacity". Article 12 (4) concerns itself with the need to guard against the abuse of such support and does so by making provision for appropriate and effective safeguards. Article 12 (5) explicitly mentions that persons with disabilities should be able to inherit, manage financial affairs and own property. Thus both on a purposive and a textual interpretation of article 12 it can be concluded that legal capacity in the CRPD has been constructed like CEDAW to include both the capacity for rights and the capacity to act.

#### **Universal Legal Capacity**

On the question whether the CRPD guarantees legal capacity to all persons with disabilities it would be necessary to note that a definition of disability has not been incorporated in art 2 of CRPD. However an inclusive definition finds place in article 1. Such definition includes persons who have long-term physical, mental, intellectual or sensory impairments. Evidently the CRPD has employed the strategy of explicitly naming certain groups in the definition in order to highlight their higher discrimination and the greater need for strategies of empowerment. If national legislations and state practices are examined, it is found that it is these groups of persons with disabilities who are denied legal capacity. The deliberations surrounding the Convention show that the need for a separate Convention for persons with disabilities was felt because the extant human rights Conventions were not disability inclusive and could not provide the requisite justification to challenge exclusionary national laws. In the face of this overarching commitment to the goal of inclusion in the Convention, it is logical to conclude that article 12 would have been drafted in consonance with this larger objective of the CRPD.

We find upon examination of the preparatory papers, that the adoption of the paradigm of universal legal capacity was questioned because it was feared that it did not adequately address the concerns of persons with high support needs. It was due to this apprehension that paragraph (3) placed an obligation on State Parties to make provision for support and paragraph (4) was drafted to

encompass a range of safeguards against abuse of support. Persons with high support needs may have been one group of persons who could have been denied full personhood and legal capacity, if the provision for support had not been made in article 12. However the combined reading of the definition of disability and the duty to provide support leads to the conclusion that article 12 has been formulated to bring within its aegis all persons with disabilities. This support could be of personal assistants or peers or may even be just a written declaration of the preferences of the person with disability. What the Convention requires is that the support should be based on trust, be provided with respect and not against the will of the person with disabilities.

#### Reservations

The last question we were required to address was whether states could enter reservations against article 12?

Article 46 of the CRPD and article 14, paragraph 1 of the Optional Protocol to the Convention, do not permit reservations that are incompatible with the object and purpose of the CRPD. Equality and non discrimination along with respect for dignity, individual autonomy and freedom to make one's own choices have been recognized as the general principles of CRPD. The general principles were included to render the object and purpose of the Convention explicit. A reservation on article 12 is antithetical to each of these principles and hence not permissible by article 46 of the Convention. Further if a reservation is entered to either circumscribe the meaning of legal capacity or to limit the persons with disabilities included under the provision the limitation will not be confined to article 12 alone but will also extend to the other rights guaranteed under CRPD be it: the right to education or the right to work or freedom of speech and expression or political participation. Such a consequence would be destructive of both the letter and spirit of the CRPD and hence unimaginable.

The CRPD by devising the supported decision making model of legal capacity has made an innovative effort to recognise the aspirations of all persons with disabilities; we have issued this legal opinion in order to assist informed understanding of this innovation.

June 21, 2008

Argentina:

Santos Cifuentes Estudio Jurídico Cifuentes y Asociados Ex Profesor Titular de Derecho Civil, Facultad de Derecho, Universidad de Buenos Aires Académico de Número de la Academia Nacional de Derecho y Ciencias Sociales Ciudad de Buenos Aires Argentina

Christian Courtis School of Law/Facultad de Derecho University of Buenos Aires/Universidad de Buenos Aires Buenos Aires Argentina (on leave) Currently: Legal Officer for Economic, Social and Cultural Rights/Director del Programa sobre Derechos Economicos, Sociales y Culturales International Commission of Jurists/Comision Internacional de Juristas Geneva/Ginebra Switzerland/Suiza

Agustina Palacios Directora de la Dirección de lucha contra la Discriminación y la promoción de Derechos Humanos, Mar del Plata, Argentina Profesora de la Facultad de Derecho de la Universidad Nacional de Mar del Plata, Argentina Coordinadora de la Sección Discapacidad de la Cátedra de Igualdad y No Discriminación "Norberto Bobbio" Instituto de Derechos Humanos "Bartolomé de las Casas" Universidad Carlos III de Madrid Mar del Plata Argentina

Australia:

Duncan Chappell Professor of Law University of Wollongong New South Wales Australia Bernadette McSherry Australian Research Council Federation Fellow Rethinking Mental Health Laws Project Faculty of Law Monash University Clayton Australia

#### Brazil:

Ana Paula Crosara de Resende CVI-BRASIL Conselho Nacional dos Centros de Vida Independente APARU - Associação dos Paraplégicos de Uberlândia Instituto dos Advogados de Minas Gerais Seção Uberlândia Advocacia Catani e Crosara Uberlândia - MG Brasil

Patrícia Garcia Coelho Catani Advocacia Catani e Crosara Uberlândia - MG Brasil

#### Chile:

María Soledad Cisternas Reyes Directora del Programa Jurídico sobre Discapacidad Facultad de Derecho Universidad Diego Portales Santiago Chile

#### Costa Rica:

Rodrigo Jiménez Professor University of Costa Rica Master Degree in Disabilities Studies San Jose Costa Rica

#### Denmark:

Holger Kallehauge Ex High Court Judge and Deputy Parliamentary Ombudsman Fhv. Landsdommer Frederiksberg Denmark

#### India:

Amita Dhanda Professor of Law NALSAR University of Law Hyderabad India

#### Ireland:

Gerard Quinn Main Statutory Chair in Law National University of Ireland Galway Ireland

Japan:

Yoshikazu Ikehara Tokyo Advocacy Law Office Hongo Bunkyo-ku Tokyo Japan

Makoto Iwai Yuri Sogo Law Office Shinbashi Minato-ku Tokyo Japan

Hirobumi Uchida Professor, Department of Private and Criminal Law Kyusyu University Hakozaki, Higashi-ku Fukuoka Japan

Mitsuhide Yahiro Nishijin Kyodo Law Office Nishijin Sawara-ku Fukuoka Japan

#### Mexico:

Santiago Corcuera Cabezut Consejero de la Comisión de Derechos Humanos del Distrito Federal Maestro (Master Degree, LLM) en Derechos Humanos Miembro del Comité de la Convención Internacional para la Protección de Todas las Personas contra Desapariciones Forzadas de Naciones Unidas México, D.F. México

Carlos Ríos Espinosa Consejero de la Comisión de Derechos Humanos del Distrito Federal Maestro (Master Degree) y Profesor del CIDE Centro de Investigación y Docencia Económica México, D.F. México

Netherlands:

Lisa Waddington Extraordinary Professor in European Disability Law Faculty of Law Maastricht University Maastricht The Netherlands

New Zealand:

Susan Jane (aka Huhana) Hickey Auckland Disability Law Mangere Community Law Centre Auckland New Zealand

Nicaragua:

Carlos Emilio Lopez Ex-Procurador de los Derechos de la Niñez Profesor Universitario en Universidades Públicas y Privadas en las facultades de sociología y derecho; Universidad Centroamericana, Univalle, Paulo Freire y Escuela Judicial de la Corte Suprema De Justicia Managua Nicaragua

#### Peru:

Juan Vicente Ugarte del Pino Presidente de la Excelentísima Corte Suprema de Justicia de Perú (1987) Magistrado del Tribunal de Justicia de Acuerdo a Cartagena Miembro Correspondiente de la Real Academia de Ciencias Morales y Políticas – España (1988) Presidente del Curatorium de Doctores del Perú Vicepresidente del Instituto de Derecho Indiano y de Estudios Clásicos Director de la Sociedad Peruana de Historia Director del Instituto Peruano de Historia del Derecho Lima Perú

United Kingdom:

Peter Bartlett Nottingham Healthcare NHS Trust Professor of Mental Health Law Faculty of Social Sciences, Law and Education University Park Nottingham United Kingdom

United States of America:

Robert Dinerstein Professor of Law American University Washington College of Law Washington, D.C. USA

Arlene S. Kanter Professor of Law Meredith Professor of Teaching Excellence Director, Disability Law and Policy Program Co-Director, Center on Human Policy, Law, and Disability Studies Syracuse University Syracuse, New York USA

Tina Minkowitz Attorney Center for the Human Rights of Users and Survivors of Psychiatry Chestertown, New York USA

Michael L. Perlin Director, International Mental Disability Law Reform Project Director, Online Mental Disability Law Program New York Law School New York, New York USA

Stephen A. Rosenbaum Lecturer in Law, University of California, Berkeley Lecturer in Law, Stanford University Staff Attorney, Disability Rights California dba Protection & Advocacy Inc. Oakland, California USA Susan Stefan Center for Public Representation Newton, Massachusetts USA

Michael Stein Executive Director, Harvard Project on Disability Harvard Law School Cambridge, Massachusetts USA

Michael Waterstone Professor of Law Loyola Law School Los Angeles, California USA