



Republic of San Marino

National Bioethics Committee of Republic of San Marino

Law no. 34 of 29 January 2010

***BIOETHICAL APPROACH TO
PERSONS WITH DISABILITIES***

Approved in the plenary session of 25 February 2013

Translated in collaboration with DPI Italia Onlus

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INTRODUCTION

In April 2011, just after its establishment, the National Bioethics Committee of Republic of San Marino (CSB) decided to undertake a general reflection on disability, a very complex and sensitive topic.

This decision stemmed from the recognition that so far disability has been largely absent from global bioethics discussions, especially in the documents of many National Bioethics Committees. Moreover, this decision was made in the awareness that the current international framework needs a thorough assessment after 6 years from the approval by the UN General Assembly of the Convention on the Rights of Persons with Disabilities.

The Republic of San Marino was one of the first States to ratify this important international document in February 2008, thus showing particular sensitivity to such an issue which is a great concern to the oldest Republic in Europe.

Aware of the great cultural and bioethical value of the UN Convention, the CSB has decided to produce a document addressing the issue of disability. Starting from such Convention, the Committee has undertaken an analysis and reflection on the principles enshrined therein, which have inspired the working modalities and the structure of this document.

First of all, I would like to highlight the innovative approach of the document. Its bioethical approach is rooted in human rights, thus overcoming any other previous approach based on welfare or medical-rehabilitation models. Therefore, the focus has shifted from disability to the persons with disability, whose human dignity is recognised since they are people having human rights. The title of the document effectively summarises this approach.

A second feature of the document is represented by the efforts made by the CSB to explicate and clarify the principles of the Convention by giving concrete examples. The goal is to have a more user-friendly approach, thus fulfilling one of the mandates to which the National Bioethics Committee of Republic of San Marino attaches great importance: the promotion of correct information and public awareness-raising of bioethical issues in the context of the promotion of human rights.

Finally, worth stressing is that in drafting the document, the CSB has complied with the requirement imposed by the UN Convention on all States Parties to closely consult with and actively involve persons with disabilities, through their representative organizations (Article 4 - General obligations). The Working Group has been coordinated by myself in cooperation with Mr. Giampiero Griffo, a CSB external expert and member of the World Council of *Disabled People's International*.

The following members immediately joined the Group: Silvia Gabotti, Raffaele Giorgetti, Lamberto Emiliani and subsequently Renzo Ghiotti, don Gabriele Mangiarotti, Nicola Romeo.

The CSB has also met with the representatives of the voluntary sector of the Republic of San Marino and members of the Association of volunteer organisations. These organisations, which have shared the philosophy underlying the document, have provided, through the Social Security Institute (ISS), data and information on the situation of persons with disabilities in San Marino. Data relate to the situation at 31 January 2013 and are included in the annex.

Therefore, such work of the CSB is carried out in the context of the promotion and application of the UN Convention, in accordance with the provisions of Article 33 thereof (National implementation and monitoring). It is finalised in a period that is particularly important to this Republic, which will host the UN Secretary-General Ban Ki-moon on 1 April 2013.

The document was approved unanimously during the CSB's session of 25 February 2013 by all the following members present: Luisa Borgia, Verter Casali, Lamberto Emiliani, Silvia Gabotti, Renzo Ghiotti, Raffaele Giorgetti, don Gabriele Mangiarotti, Nicolino Monachese, Nicola Romeo. Valentina Chantal Francia gave her approval via videoconference. The President of the Committee, Virgilio Sacchini, and Paolo Di Nardo, who did not participate, gave their approval.

The CSB Vice-President and
President of the session of 21 January 2013

Luisa Maria Borgia

FOREWORD

The issue of disability has long been absent from international bioethical reflections for a variety of reasons, such as:

- the complexity and the wide-ranging nature of the issue. There are multiple forms of disability (physical, sensory, mental, intellectual or behavioural) and each of them has many implications, which make it extremely difficult to deal with such issues in a comprehensive and systematic manner;
- the lack of a unanimously agreed and shared definition of disability, which has made it difficult to identify the subject of bioethical considerations;
- the linguistic fluidity and semantic evolution characterising such issue over the centuries: from the ancient terms with a very derogating meaning (i.e. cripple, invalid or handicapped) to the more modern ones with a less negative connotation (differently-abled) and the current one (person with disabilities). The latter shifts the focus from the functions and characteristics to the ontological dimensions of the human being, whose inherent nature is not dependent on his/her qualities;
- the difficulty of addressing, without prejudice, an issue considered a taboo for centuries, since it has always been associated with unclear, irrational situations, which science has studied and understood only in recent years;
- the lack of awareness, on the part of persons with disabilities, of their human dignity. Such lack has always prevented them from being involved in public debate. Indeed, only since the 1970s, when movements and associations of persons with disabilities and their family members developed, disability has finally been given an official place in the public debate.

In the light of the aforesaid, international institutions did not pay attention to the issue of disability until 2006, when the UN approved the Convention on the Rights of Persons with Disabilities. Nevertheless, in dealing with this issue with difficulty, bioethics bodies do it only indirectly¹ and give rise to a paradox: persons with disabilities, among these women, children and old people with disabilities, are the most vulnerable and bioethics can and must take far-reaching action vis-à-vis such people, so that the essential principles of beneficence, autonomy and justice be applied and implemented.

In the light of these considerations, the CSB has decided to undertake a reflection on disability leading to a document. Aware of the complex work and the responsibility incumbent on the first international work on such topic, the CSB has decided to draw up the document on the

¹ By way of example, at present no National Bioethics Committee has prepared a document on the subject of disability. On 17 March 2006, the Italian National Bioethics Committee published a document titled "Bioethics and rehabilitation" (http://www.governo.it/bioetica/testi/BIOETICA_riabilitazione.pdf)

basis of the UN Convention, prompted by the conviction that such Declaration represents from a bioethical point of view, a "point of no return", a sort of cultural earthquake, the impact of which may be fully assessed only in the coming years.

Indeed, the Convention places the issue of disability in the political context of citizenship and equality and includes it in the concept of human dignity.

In the light of the new approach defined in said Convention, disability is included in the recognition of human rights. Therefore, the right of citizenship is given back to persons with disabilities, no longer on account of convictions and conventions regulating individual countries, but on account of a universal criterion having its political basis in human dignity.

Building on the recommendations contained in the UN Convention and implementing the motto of the international movement of persons with disabilities ("Nothing about us without us"), the CSB has decided to prepare this document in cooperation with a member of the World Association *Disabled Peoples' International* to ensure the most correct and impartial overview of the issue.

THE CONDITION OF PERSONS WITH DISABILITIES IN THE WORLD

In the world, persons with disabilities are about 1 billion² (15% of the global population) and 82% live in developing countries. Data on persons with disabilities are inadequate and insufficient and they are limited to health-care and assistance. In these countries, 90% of persons with disabilities do not have access to rehabilitation services and appropriate basic services. Only 5% of children with disabilities have access to formal education.

In addition thereto, more than 80% of persons with disabilities worldwide are unemployed and they are often segregated in special institutions and centres³. In Europe, more than 60% of children with disabilities attending primary school are segregated in special classes or schools⁴. In most developing countries, there are no adequate health services. Therefore, life expectancy of persons with disabilities is much lower than that of their peers living in industrialised countries⁵. The disability condition is both a cause and an effect of poverty, because persons with disabilities are subject to discrimination and lack of equal opportunities. Therefore, they meet obstacles and barriers to their social participation and their human rights are violated every day. Society's low regard for persons with disabilities results in very strong social stigma⁶ having consequences in all fields of economic, cultural, political and social life. Being discriminated and being subject to unequal opportunities determine social exclusion. This condition gives rise to additional costs and progressive impoverishment of individual capacities and of social protection measures. Therefore, persons with disabilities are poor and, at the same time, they are impoverished.

As a result of the stigma associated with disability, there is often the tendency to see only the mental and physical disability instead of the person and his/her overall qualities⁷. Such view influences many sectors of society by giving a false picture of the situation faced by persons with disabilities and influencing medical, technical and social practices.

With a view to overcoming such stigma, the Convention requires to adopt a new approach towards disability. As a matter of fact, all over the world the medico-legal assessment of functional diversity, through a number of benchmarks, is the form used to identify persons with disabilities (disability assessment), since the objective of States is to identify the beneficiaries of financing and support measures and not the real condition of disability.

² World Health Organization (2011). *World report on disability*. Malta 2011, page 29.

³ In the European Union of 25 members, a recent research activity financed by the European Commission has produced a report on the situation of persons with disabilities living in institutions in the 25 Member States (website: www.community-living.info), highlighting that there are 2,500 large institutions hosting 500,000 people. See also the figure of 1,200,000 persons with disabilities living in institutions provided by the European initiative for the support of life in the community, <http://www.community-living.info/index.php?page=204>

⁴ Please, see the website of the European Agency for Development in Special Needs Education with regard to the 2008 *countries date report on school inclusion in European countries* (www.european-agency.org).

⁵ For instance, in Tanzania the life expectancy of a person with spinal cord injury ranges from 4 months to 2 years.

⁶ Goffman, E. (1983). *Stigma: Notes on the Management of Spoiled Identity*. Ombrecorte, Verona 1983.

⁷ Basaglia, F.(2000). *Brazilian conferences*. Edited by Ongaro Basaglia F.; Giannichedda M. G. Milan, 2000.

Undoubtedly, the status of disability affects a person regardless of whether he/she is a worker (a public or private employee), a worker with few years of contributions, a housewife, a teenager or an old person. Similarly, a disability resulting from an accident at work or occupational disease has the same impact on the person as a disability caused by non-occupational accidents or spontaneous, congenital or acquired diseases.⁸

All disabilities give rise to a need which is not related to the profession or personal data of the individual concerned, but to the nature, severity and curability of the disease, as well as to individual subjective aspects and social limitations.

The criteria for the allocation of funds and benefits, which today are fragmented and different since they are based on the cause of a disability, should be revised. The many categories of financing measures should be unified, so as to guarantee equal funds and benefits for the same type of impairment.

The current approach is based exclusively on a medical/mechanical model of disability, assessing a person's health conditions according to parameters and in a subjective manner. The new definition of person with disabilities introduced by Article 1 of the Convention on the Rights of Persons with Disabilities requires to change the assessment approach. According to this new definition, the concept of biological damage (major and essential damage), not strictly limited to the physical (anatomical) and/or functional component (ability to work) is associated with the social component of the individual, who is integrated and interacts with others by relying on his/her cognitive and emotional skills. It must also take account of the living conditions (assessed homogeneously through instruments such as ICF) and of all support actions (rehabilitation and habilitation) required for social inclusion⁹. Also in this case, the traditional form of assessment, assigning disability rates to persons with disabilities, underlines negative aspects associated with disability. Although this is a science-based approach, very different conditions are assimilated (i.e. to be in a wheelchair is assimilated to the inability to represent oneself) by using for a disabled person some parameters of invalidity that may adversely affect the proper assessment of his/her abilities¹⁰.

This is a change of approach due to the increasing attention paid to the individual and his/her central role deserving full health protection (according to the broad definition provided by the World Health Organization of person's well-being), regardless of the capacity to generate income.

⁸ Iacone G., Buccelli C. *L'invalidità Civile. Aspetti Sostanziali, Processuali, Medico Legali*. Wolters Kluwer Italy, 2008.

⁹ Alves I., Bosisio Fazzi L., Griffo G. *Human Rights, Persons with Disabilities, ICF and the UN Convention on the rights of persons with disabilities*, Edizioni Comunità, Lamezia Terme (CZ), 2010.

¹⁰ For a reflection on the topic, see Dossier. *La definizione della disabilità e la sua valutazione*, pg. 20-33 in HandylexPress, A. IV (2012), n. 14, Padua.

Such an innovative, modern and effective system to evaluate personal injuries may be implemented through limited cultural and conceptual "burdens". At the same time, it also ensures, with respect to full recovery of personal injuries, compliance with the mandatory principles of solidarity and subsidiarity in order to reduce or eliminate disabilities.

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The UNESCO Universal Declaration on Bioethics and Human Rights (2005)¹¹ has clearly underlined the need that "ethical issues raised by the rapid advances in science and their technological applications should be examined with due respect to the dignity of the human person and universal respect for, and observance of, human rights and fundamental freedoms". The relationship between human rights and bioethics had already been discussed by UNESCO in other documents¹², but such relationship is clearly outlined in the Declaration. Indeed, the first principle stressed by the Declaration reads as follows: "*1. Human dignity, human rights and fundamental freedoms are to be fully respected. 2. The interests and welfare of the individual should have priority over the sole interest of science or society*" (Art. 3).

Therefore, it has been recognised for the first time and unequivocally that the activities concerning human beings must respect human rights, which accordingly become the reference framework for bioethics. This document is particularly important to persons with disabilities subject to negative stereotypes and cultural prejudices. Such stereotypes and prejudices have significantly influenced and are still influencing behaviours deemed to be bioethical, which, however, often violate the human rights of said persons.

The entry into force of the UN Convention on the Rights of Persons with Disabilities¹³ on 3 May 2008¹⁴ further clarified that such persons are subject to continuing violations of their human rights. Therefore, they must be protected, also from a legal point of view (Art. 5). Thus, the condition of persons with disabilities is set firmly within the international framework of globalisation of human rights. On the basis of such framework, which was established after the Second World War, protection of human rights has been extended to women, children and migrants, shaping a world where all human beings "are entitled to rights"¹⁵.

The CSB considers the Convention a cultural reference model representing a historical event, the scope of which can be assessed only in decades. This text introduces many cultural,

¹¹ In 2005, in the occasion of the 33rd session of UNESCO General Conference, the Member States unanimously adopted the Universal Declaration on Bioethics and Human Rights.

¹² The Universal Declaration on the Human Genome and Human Rights, adopted by UNESCO's General Conference on 11 November 1997 and the International Declaration on Human Genetic Data, adopted by UNESCO's General Conference on 16 October 2003.

¹³ The term "persons with disabilities" is the one accepted at the international level. For clarifications on the use of this expression, please see *Le buone prassi nell'uso delle parole: le parole sono pietre* (2005), in *Le idee vincenti. Esempi di buone prassi nello sviluppo della cultura imprenditoriale e dell'accoglienza*. Pesaro, project Equal Albergo via dei matti numero zero, [2005].

¹⁴ Approved by the UN General Assembly on 13 December 2006. The Convention was ratified by San Marino through Parliamentary Decree no. 19 of 4 February 2008. As of today, more than 126 States have ratified it. See UN website at www.un.org/disabilities

¹⁵ Rodotà S.: *Il diritto ad avere diritti*. Laterza, Rome - Bari 2012. Romanach Cabrero J. (2000) *Bioetica al otro lado del espejo. La vision nde las personas con diversidad funcional y el respect a los derechos humanos*. Santiago de Compostela, Edicion Diversitas-AIES.

social, political and technical changes. It has contributed to a shift in thinking about persons with disabilities: from the traditional interpretation of disability regarded as an individual and medical problem to the awareness that persons with disabilities are discriminated and they do not benefit from equal opportunities. Based on this Convention, persons with disabilities, who were previously considered as invisible citizens and were excluded from society, are now treated as persons with human rights. Moreover, there has been a change in the framework, reflecting a shift from an approach based on assistance and health policies to an approach based on social inclusion and mainstreaming policies¹⁶. Such changes in the approach refer to a social model of disability based on the respect for human rights and are summarised in the motto of the international movement of persons with disabilities "Nothing about us without us"¹⁷.

The CSB is aware that such Convention has introduced a radical cultural and bioethical change, resulting from a long-lasting process¹⁸, which will have wide repercussions not only in the field of disability. Indeed, the new awareness that disability is an ordinary condition experienced by every human being in their life requires society to take it into consideration in all decisions concerning social development and organisation. The protection of human rights, social inclusion policies and the organisation of society based on *Universal design*¹⁹ concern all societies in general.

The Convention marks a shift in thinking about persons with disabilities: before recognising their needs, it is necessary to recognise their human rights. Such shift also clarifies the task entrusted to society: to guarantee violated rights by eliminating barriers, obstacles and prejudices, as well as unequal and discriminatory treatment.

The new concept enshrined in the definition of disability ("disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others") focuses the

¹⁶ Mainstreaming is an anti-discrimination strategy based on which the implementation of the principle of non-discrimination is no longer regarded as an individual objective to achieve as if it were a specific area of action, but rather as a principle to be integrated in all possible fields of public action: from employment to education and external relations. Therefore, according to the principle of mainstreaming, before the adoption of a certain measure, public authorities should assess whether such measure would give rise to discrimination, so as to prevent any negative consequence and to improve the quality and effectiveness of their policies. The definition is provided for in Article 29 of Directive 2006/54/EC.

¹⁷ Said motto conveys a message for the achievement of inclusion in accordance with the provisions of the Convention (Article 4, paragraph 3): "In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations".

¹⁸ The first UN document on disability dates back to 1971 and is the Declaration on the Rights of Mentally Retarded Persons. See Griffio G: *I diritti umani per le persone con disabilità*, in *Pace Diritti Umani*, n° 3, September-December 2005, pages 7-31.

¹⁹ It is the approach to the design of policies, environments, goods and services taking into account all human diversities.

attention on the interaction between the characteristics of persons and the way in which society takes them into consideration.

Another new aspect introduced by such document is the concept of progressive social inclusion of persons with disabilities. Indeed, as they fully enjoy all human rights, they regain their role as citizens participating in society, which shall take them into account in all its policies, on an equal basis with others.

Thus, the objective of the Convention is to prohibit all discriminations based on disability²⁰ and to ensure equal and effective legal protection against discrimination in all sectors. To this end, States shall take all appropriate steps to ensure that "reasonable accommodation"²¹ is provided to eliminate unequal treatment and barriers.

Furthermore, since there are conditions giving rise to multiple discriminations, the Convention pays special attention to women and children with disabilities in two specific articles (Articles 6 and 7).

The new approach of the Convention is aimed at overcoming the traditional one, based on segregation and institutionalisation, by promoting life in the community, including through the support of independent living (Articles 19 and 20), behaviours respecting human rights of persons that cannot represent themselves (Article 12), access to all rights on an equal basis and without discrimination.

Being it a relationship between the characteristics of an individual and the social and physical environment, disability can be prevented not only in the health field by reducing the consequences of diseases, accidents and ageing, but also in the social sphere, by removing obstacles and barriers, providing technical devices and support and creating the conditions for eliminating all kinds of discrimination and unequal treatment²².

Given that disability is an experience that every human being encounters during his or her life, as highlighted by the World Health Organization (WHO), policies to eliminate it concern society's general policies. They represent a new challenge for this millennium and an investment for the future.

²⁰ *Art. 2 (Definitions): "Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation".*

²¹ *Art. 2 (Definitions): "Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".*

²² See the research activity promoted by the European Commission (2011) *Study of Disability in EC Development Cooperation. Final report.* by Peter Coleridge, Claude Simonnot and Dominique Steverlynck. Brussels, 2010.

The CSB believes that a bioethical reflection on this new paradigm of disability in the light of respect for human rights may contribute to removing negative cultural stereotypes and prejudices.

EVOLUTION OF DISABILITY MODELS

In order to understand the evolution of the concept of disability, it is necessary to outline the role assigned to persons with disabilities in different societies²³. The Greeks and the Romans, societies of warriors that allowed the infanticide of children with evident malformations or fragility, did not leave space to the survival of persons with disabilities, the only exception, even if rare, was the belonging to ruling classes. Also Aristotle claimed that whoever was born deaf would become senseless, without reason and incapable of understanding, since communication was deemed essential to knowledge.

Even the role of religion has not always contributed to overcoming the negative stigma that affected persons with impairments²⁴. Religions have played a twofold role: on the one hand, they have given a central role to human dignity²⁵ (an essential element of Christianity, in a Roman slavery society and a Medieval one based on serfdom), while on the other hand they have endorsed negative stereotypes. Pagan religious practices related to scapegoating often used to involve persons with disabilities²⁶, thus contributing to the creation of a negative social stigma.

Although health-care and charity activities²⁷ developed in convents during the Middle Ages, such period accentuated the negative vision that built a direct correspondence between evil (often

²³ Information found in the essay by Giovanni Padovani to be published with the title *Storia del trattamento sociale delle persone con disabilità* and by Fioranelli M.: *Il decimo cerchio. Appunti per una storia della disabilità. Presentazione di Giorgio Cosmacini*. Laterza, Rome - Bari 2011.

²⁴ See, for example, the Book of Leviticus 21: 16-20. In this regard, Martin Luther, talking about babies born with congenital malformations, said: "Take retarded children and throw them in the river"; see also the theory of Buddhist reincarnation that attributes a value of punishment to the condition of disability, caused by an insufficiently worthy previous life. See also *Fondazione Facite*, Fish Calabria: *Il mio posto in parrocchia. Ricerca sull'integrazione dei disabili nella comunità cristiana*. Catanzaro, 2000.

²⁵ However, the question about the dignity of the human being (whatever is his/her condition) remains open for the Bible text. Indeed, in the Jewish tradition, the following definition of disease is provided in the reinterpretation of the Pentateuch: "Abraham introduced old age, Isaac introduced suffering, Jacob introduced illness" (Genesis Rabbah, 65:10) The illness introduced by Jacob was lameness. This aspect was also mentioned in the text of the Song of Songs and was applied to the Bride coming up from the desert leaning on her beloved because she is lame (see Song of the Songs, 8:5). In the Gospel, the poor and the sick are described by Jesus Christ as representing his very person (see, for instance the parable of the Good Samaritan). Giving aid to the sick means, therefore, to give aid to Christ. This is a reason constituting an important change in respect of the goal of providing assistance to the sick. The third important turning point is related to the fact that in the Gospel Christ heals the body of the sick and also their soul. This means, that for Christ the notion of health has a deeper meaning, which is not limited to body health.

²⁶ Girard R.: *Violence and the Sacred (La violenza e il sacro)*, Italian translation, Adelphi, Milan 1980.

²⁷ In the High Middle Ages, convents had a hospice (from *hospes*, meaning guest) where the sick and the poor used to be hosted. In the first period of monasticism, cities, urban structures and any social service were in crisis. Therefore, at that time the only places of reference were monasteries. They were entrusted with the task of providing assistance to the sick, especially pilgrims who, during their journey, became ill and stopped at the convent. Since the 6th century, assistance has been provided indiscriminately to the pilgrim falling ill or to the wandering sick in order to allow the viator, that is to say the pilgrim, to start his/her journey again. For this reason, the monastery is also a place of care (inside the hospices). See the website http://www.culturacattolica.it/default.asp?id=172&id_n=20028.

the devil) and ugliness (a person with malformations). The iconography of the era linked them to evil and gave these persons the role of mendicants²⁸. In the same period lazarettos²⁹ were established. They used to be outside of the walls of the city and gave shelter to people suffering from infectious diseases (victims of the plague and lepers). The sick were not assisted by medical practitioners, but rather by religious people and/or lay people belonging to confraternities. However, mercy towards the suffering also included healthcare activities to recover health³⁰. Such attention paid to healthcare is demonstrated by the fact that between the 12th and the 13th centuries a distinction between the poor and the sick was made and cooperation was established between those taking care of the body and those taking care of the soul. However, such experience led to the adoption of a segregating approach to ill people, which influenced both medical and social protection treatment models of the subsequent centuries.

The first vague and uncertain definitions linked to persons with disabilities were born in medical-welfare contexts and testify how the negative stigma is strongly present even in terminology: crippled, suspicious, crooked, hunchback, lame, etc. The industrial revolution developed a model of human beings connected with production, to which persons with any kind of impairment (whether physical or mental) could not correspond. The Thirty Years' War (1618-48) caused a very high number of injured, mutilated and impaired people. Therefore, facilities were built to host such people³¹, such as workhouses in England, *Les Invalides* in Paris and private and public institutions, often of a charitable nature. At that time, they were places providing protection from certain death, based on the cultural model of Medieval lazarettos. They hosted any socially undesirable person, including persons with disabilities. Segregation in places away from society was accompanied by forms of social control, because these facilities hosted different categories of socially undesirable people, such as sick and invalid persons, socially deviant people (unmarried mothers, minor heretics, etc.), politically disturbing persons (political opposers, etc.). In the 18th and 19th centuries a true science of segregation and of segregating places

²⁸ See, for example, the paintings by Brugel.

²⁹ Their name refers to Lazarus, who was raised by Christ from the dead.

³⁰ Therefore, the word "salus" in medieval Latin means both physical health and spiritual/moral/psychological healing. The concept of *valetudo* of the classical period, referring only to physical health, is replaced by the concept of *salus*, i.e. salvation. With regard to the sick, the concept of *salus* means to go through the suffering or pain of the disease as it were an opportunity for growth and strengthening of the faith. For those providing care and assistance to the sick, the concept of *salus* conveys the idea that the persons providing aid and being healthy can learn much from the sick: they are called upon to help them and are involved in the plea to God for their healing. The concept of *salus* is also strictly connected with the cause of the disease. In the Medieval conception, on the one hand the natural origins of diseases were recognised, while on the other hand the severity of the disease was linked to the great issue of human limits, suffering and original sin. Finally, as previously stated, sickness was seen as a sign of God's correction, an instrument of His mercy. In other words, it appeared as a sort of spiritual treatment, since it made people better and closer to God (see, for instance, the story of Job told in the Bible). This also explains why the poor, *pauper*, and the sick, *infirmus*, were placed in the same category in the High Middle Ages, that is to say the category of weak human beings needing God's and people's help and assistance.

³¹ Foucault M.: *History of Madness*, Rizzoli, Milan 1963.

developed³²: mental hospitals and assistance institutions, mainly of a religious character, were established. Such places provided charity activities, para-scientific medical practices and strong social control³³. In the second half of the 19th century, legislation on social protection of workers was adopted (the pioneer was the social insurance regime introduced in Bismarck's Prussia). Such legislation defined a new approach to disabilities caused by accidents at the workplace, for which adequate compensation was provided. In the aftermath of the First World War 8,500,000 injured survivors needed social protection covered by the granting of subsistence pensions.

These historical and social elements contributed to consolidating a mainly medical and welfare interpretation³⁴ of the condition of persons with disabilities. Nazi campaigns for the extermination of persons with disabilities, considered useless and costly lives for society, were the first proof of the subsequent Holocaust of the Jews. However, such campaigns were concealed and kept hidden until the 1970s as they were a lesser evil of the horrors of the Third Reich³⁵. After the Second World War and the numerous subsequent local wars, all shocked survivors or with functional impairments experienced conditions of social disadvantage and lack of equal opportunities suffered by persons with disabilities. For this reason, social protection legislation was adopted to cover other categories of beneficiaries (from war invalids to work-related and civil invalids). Such legislation focused not only on access to care and welfare services, but also on measures supporting civil rights (rehabilitation, employment and education).

Such combination of treatment, vision and approach is commonly defined as the medical/individual model, putting the blame on persons with functional diversity for not being able to live in the places and with the rights of the other citizens if not after they have been rehabilitated and healed.

In the 1970s, following the civil rights movements, the social model of disability³⁶ is opposed thereto. Such model attributes to society the responsibility for the social exclusion of persons with disabilities, that has produced obstacles, barriers and limitations of access to goods

³² A famous example of a place of segregation is Jeremy Bentham's prison called *Panopticon* (1791), where spaces and control potentials represented a "new mode of obtaining power of mind over mind, in a quantity hitherto without example". All places of segregation drew inspiration from this model.

³³ Foucault M.: *Surveiller et punir. Naissance de la prison*. Gallimard, Paris 1975.

³⁴ Schianchi M.: *La terza nazione del mondo*. Feltrinelli, Milan 2009.

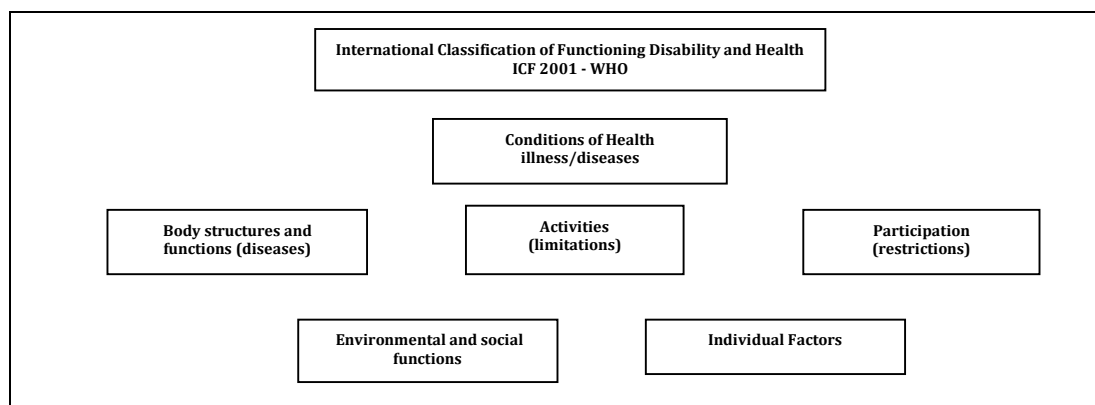
³⁵ Kuntz D.: "Nazi 'Euthanasia' Programs". ed. *Deadly Medicine: Creating the Master Race* by Michael Burleigh. United States Holocaust Memorial Museum/University of North Carolina Press, 2004. Gallagher H. G.: *Holocaust: Disabled Peoples*. In [Century of Genocide: Critical Essays and Eyewitness Accounts](#), edited by Samuel Totten, William S. Parsons, and Israel Charny, 205-230. New York, 2004. Evans S.: *Forgotten Crimes: The Holocaust and People with Disabilities*. Chicago 2004.

³⁶ See *The individual and social models of disability* by Oliver M. Paper submitted at the *Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with established locomotor disabilities in hospitals*, 23 July 1990. See also *The Politics of disablement* by the same author. Basingstoke Macmillans, 1990.

and rights. During the same period, movements also developed against the institutionalisation of persons with disabilities affected by the social stigma³⁷ and for independent living³⁸.

This process of elaboration of new heuristic instruments of reality, which were able to describe in a different way how society treated persons with disabilities, achieved a first partial result by influencing the WHO ICDH classification (1980)³⁹. Indeed, this classification recognised at a scientific level that the situation experienced by persons with disabilities had to be analysed on the basis of a model of disability focused on a new cultural and social approach, even if it is still erroneously invalidated by a medical determinism. The subsequent developments in the international debate within the United Nations highlighted the need to create a new cultural instrument based on equal opportunities for persons with disabilities and addressed to societies able to welcome everyone. This led to the drawing up of the Standard Rules for the Equalization of Opportunities of Persons with Disabilities (UN, 1993).⁴⁰

FIGURE 1 BIO-PSYCHOSOCIAL MODEL OF DISABILITY OF ICF-2001-WHO



This new approach required a review of the ICDH, which led to the *International Classification of Functioning, Disability and Health* (2001⁴¹), approved by the WHO Assembly and known with the acronym ICF. Besides being a classification, ICF is a model for approaching disability: a bio-psycho-social model (Figure 1).

³⁷ For instance, the movement led by Franco Basaglia for the closure of mental institutions.

³⁸ For documents on independent living, please visit the Internet website <http://www.independentliving.org/>.

³⁹ World Health Organization. ICDH. Bergamo, 1980.

⁴⁰ It contains the definition of "equalization of opportunities" for persons with disabilities. "24. The term "equalization of opportunities" means the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disabilities. 25. The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. 26. Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services. The text of the Standard Rules can be downloaded from the following website: <http://www.un.org/documents/ga/res/48/a48r096.htm>

⁴¹ See the website <http://www.who.int/classifications/icf/en/>

Indeed, ICF underlines that disability is a social relationship depending on the health conditions of the interested person and the environmental and social conditions in which people conduct their lives. Whenever such conditions do not take the functional diversity of the person into consideration and do not adjust the context in which he/she lives accordingly, barriers and obstacles limit social participation. On the contrary, with the introduction of facilitators making spaces and opportunities available to all citizens, functional diversity does not automatically mean disability.

Therefore, disability is not a personal condition, because it is not true that a limitation in the use of bodily functions and structures always entails a reduction in his/her capacity and performance.

ICF disability model is a substantial step forward to make all professionals working with persons with disabilities understand the environmental and social dimension of disability, even if it is still a model based on medical aetiology describing the functional diversity of a body part as an element separated from the adaptation capacity of human beings. Moreover, the picture ICF gives of the conditions in which persons with disabilities live is substantially a static one, since it does not consider the dynamic aspects which individual and social empowerment actions may produce. In addition, at the time of its approval, the human rights approach was not fully perceived in the international debate and other 5 years had to elapse before it became an international reference standard and rule with the UN International Convention on the Rights of Persons with Disabilities (2006)⁴².

The most recent model of approach to disability, based on respect for human rights, has introduced major changes to the ICF model (Figure 2):

- a) the first difference can be inferred from the description of causes: ICF states that health conditions determine a potential disability, while the Convention is based on general principles among which particularly important is "respect for difference and acceptance of persons with disabilities as part of human diversity" (art. 3). Irrespective of its cause and nature, functional diversity is part of human diversity. The element compromising the physical functioning of the body interacts with personal and social factors and produces, in many cases,⁴³ a resilience often confused with courage. As a matter of fact, it is the capacity to accept one's conditions and adjust one's living conditions so as to take account of functional diversity in daily activities. As a consequence, it would be more correct to define functional impairment as one of the features of a person and not "the distinguishing feature", otherwise that person could be identified with that single feature. Therefore, according to the Convention model, instead of talking of diseases affecting body structures

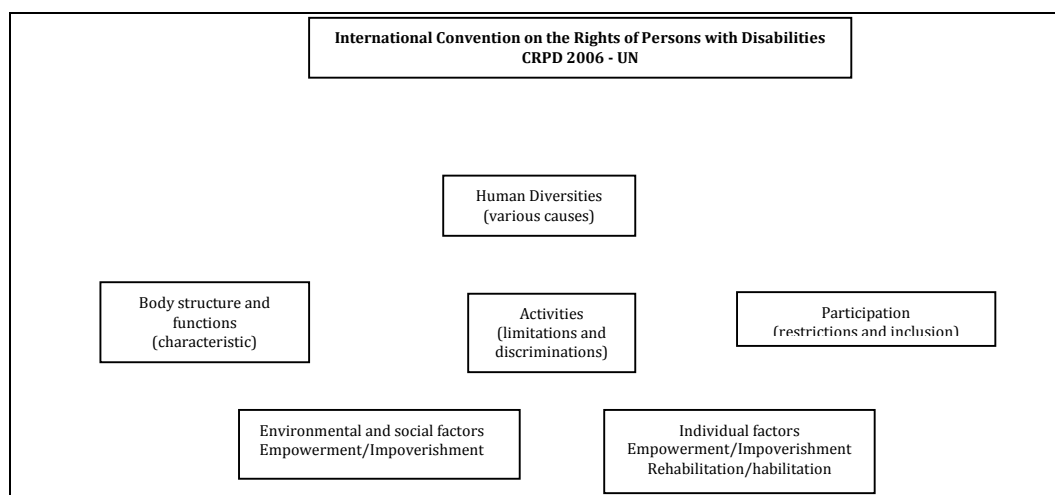
⁴² For the English text see website <http://www.un.org/disabilities/convention/conventionfull.shtml> .

⁴³ From a psychological point of view, resilience is the ability to cope with traumatic experiences in a positive way and to organise one's life despite difficulties. It is the capacity to "rebuild" oneself and remain sensitive to the opportunities life offers, without losing one's humanity (<http://it.wikipedia.org/wiki/Resilienza>).

and functioning, it would be better to use the term "features" when referring to people, on the basis of human diversity, which does not only include ethnic, cultural and social background, life experiences and DNA but also physical and functional ability of persons.

- b) In ICF the description of activity limitations is insufficient since inequality in treatment is not taken into consideration. If we use ICF in the educational context, for example, it is not possible to distinguish whether the disabled pupil is attending an ordinary class or is segregated in a special class. Therefore, the concept of discrimination should be considered, since it also determines participation modalities: inclusive or discriminatory.
- c) Other concepts upgrading the ICF model are those related to inclusion (parallel to the that of participation, which may be applied both in segregated and ordinary contexts with a totally different value), incorporation and integration. Through **incorporation** the right of persons with disabilities to be part of society is guaranteed but they are kept separated from the others (in a special institute or class, for example), in a passive condition or in a context of dependency and treatment. The decision on how they should live and be treated is not made by the persons with disabilities or their families, whenever they cannot represent themselves, but depends on decisions made by other stakeholders (physicians, public institutes staff, etc.) Incorporation is often based on a compassionate and welfare approach.

FIGURE2 THE BIO-PSYCHOSOCIAL MODEL OF DISABILITY BASED ON RESPECT FOR HUMAN RIGHTS (UNO 2006)



Integration on the contrary is the process which guarantees persons with disabilities the respect for their rights within ordinary contexts, where all people live, without adjusting rules and principles governing the structures they live in. This approach is still based on the medical model since the prevailing concept is that persons with disabilities are special and need to be supported through mainly technical interventions. Integration is not a full recognition of dignity and legitimacy: the person must adjust to already defined social rules and remain, by so doing, a guest

of the community which welcomes him/her with compassion, according to the economic resources available.

Inclusion is the concept prevailing in the most recent international documents: the person with disabilities is considered a citizen to all effects and consequently entitled to the same rights as the other citizens, is part of society and must benefit from all goods, services and policies. It is recognised that the way society is structured creates obstacles, barriers and discriminations which must be removed and transformed. Persons with disabilities are therefore full members of society, have the right to participate in choices concerning the organization of society and its governing rules and principles. The latter should be redefined taking into account all members of society. In other words, persons with disabilities are no longer guests but an integral part of society. At the basis of this concept is the social model of disability, based on respect for human rights, which underlines the responsibilities of society in creating conditions of disability. Inclusion recognises human diversity and takes account of it in the rules governing society, in the production of goods and in the organization of services. The human right to be included does not depend on the resources available but rather on the awareness that all human beings have the same rights⁴⁴.

⁴⁴ Such approach entails the definition of inclusion policies in terms of economic sustainability. It is not appropriate, for example, to link support measures to individual insurance forms, since often persons with disabilities do not have access to work. It would be better instead to include support measures in the policies financed through ordinary taxation.

A LEGAL APPROACH BASED ON HUMAN RIGHTS AND THEIR PROTECTION

The ratification by San Marino⁴⁵ of the UN Convention on the Rights of Persons with Disabilities provides a new legal, cultural and political reference framework. Since that date persons with disabilities do not have to ask for the recognition of their rights any longer but ask for their application and implementation, on the basis of respect for their human rights. It is a deep cultural and political transformation. Indeed, recognition of needs has been replaced by recognition of human rights. People with disabilities become an integral part of any civil society and enjoy the same rights, so that their "full and effective participation in society on an equal basis with others" is guaranteed.

The definition of the concept of disability in the Convention (preamble, letter e) and its General Principles (art. 3), which do not refer to health conditions but underline values never applied before with reference to persons with disabilities⁴⁶, redefines the legal protection reference framework for all States^{47,48}.

The Convention stresses that the living conditions of persons with disabilities is a matter of human rights. Every time that a person with disability is treated differently without justification, he/she suffers a discrimination, i.e. a violation of his/her human rights⁴⁹.

⁴⁵ On 4 February 2008 the Republic of San Marino ratified the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol, while on 26 February 1998 it had ratified the Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine. Hereunder is a list of laws in force in San Marino protecting people with disabilities: Law n. 141 of 21 November 1990 "Framework law on the protection of rights and on social integration of people with disabilities"; Law n. 71 of 29 May 1991 "Access to employment for invalid and disabled people"; Law n. 137 of 29 October 2003 "Family supporting measures"; Law n. 92 of 30 July 2007 "Extension of benefits envisaged in art. 5 of Law n. 137 of 29 October 2003"; Law n. 134 of 30 November 1995 "Rules on issuance of driving licence"; Law n.1 60 of 21 September 2010 " Rules on Social and Service Cooperation"; and, in the field of education, Law n. 60 of 30 July 1980 "Reform of the school system"; Law n. 37 of 4 March 1993 "Rules on vocational training and employment promotion policies"; Law n. 21 of 12 February 1998 "General rules on education" and Law n. 68 of 25 May 2004 "Rules on socio-educational services for early childhood".

⁴⁶ "a) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; b) non-discrimination; c) full and effective participation and inclusion in society; d) respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; e) Equality of opportunity; f) accessibility; g) equality between men and women; h) respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities".

⁴⁷ D'Errico A., Ferrajolo V., Griffo G. *La tutela legale della discriminazione fondata sulla disabilità*. LPH, Caserta 2010.

⁴⁸ There are no data or statistical reports in San Marino on discriminations suffered by people with disabilities. Some examples of discrimination can be inferred from the Italian situation: unemployment rate in the Italian ordinary labour market (October 2010) is equal to about 11% and reaches 76% for persons with disabilities but, while the ISTAT (Central Statistics Institute) publishes data on unemployment every 3 months, unemployment data for disabled individuals date back to 2009. Then, if we compare female unemployment, figures show that in the ordinary labour market female employment is equal to 46%, which drops to 36% in case of disabled women. Another example concerns mobility: access of people on wheelchairs to trains is possible only for 5-10% of services, compared to 100% for all other passengers.

⁴⁹ For this reason the Convention (art. 5 - Equality and non-discrimination) states that *"all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law."*

Anti-discriminatory provisions were introduced in 1990 in the United States of America with the American Disability Act. Subsequently, they were implemented in other Anglo-Saxon countries like Australia, New Zealand and United Kingdom, where common law is in force. Such provisions prohibit any unjustified different treatment of members of stigmatized groups (women, the elderly, migrants, people belonging to a different ethnic group or having a different culture, colour or sexual orientation). Any person feeling that he/she has been discriminated against can bring an action before court and claim compensation for harm suffered (physical and immaterial) and force the interested institute or person to remove the condition causing discrimination by means of reasonable accommodation. Such legislations have introduced an independent authority in charge of informing, promoting and giving opinions (an Ombudsman or a National Commission like in the United Kingdom). Also the European Union, in the Lisbon Treaty⁵⁰, provides for a non-discrimination clause, strengthened by the Charter of Fundamental Rights of the European Union⁵¹, and underlines that protection of human rights shall be immediately accessible by any citizen even if economic and social rights are attained progressively, according to the resources available. In other words, for any citizen, the human right to non-discrimination is seen as a perfect subjective right.

In defining discrimination on the basis of disability,⁵² the UN Convention specifies that discrimination occurs when someone is treated differently without any justification (*distinction*)⁵³, when someone is excluded from a right or benefit (*exclusion*)⁵⁴, when access to a service or right is

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds. 3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided".

⁵⁰ Lisbon Treaty, Article 19 (former art. 13 of the Treaty on the European Union) 1: *Without prejudice to the other provisions of the Treaties and within the limits of the powers conferred by them upon the Union, the Council, acting unanimously in accordance with a special legislative procedure and after obtaining the consent of the European Parliament, may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.*

⁵¹ See articles 21 and 26 of the Charter of Fundamental Rights of the European Union. Article 21 - Non-discrimination: *Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.* 2. *Within the scope of application of the Treaty establishing the European Community and of the Treaty on European Union, and without prejudice to the special provisions of those Treaties, any discrimination on grounds of nationality shall be prohibited.* Article 26 - Integration of persons with disabilities: *The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.*

⁵² Convention on the Rights of Persons with Disabilities, art.2 "*Discrimination on the basis of disability*" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.

⁵³ For example, when information is not provided in the adequate form to the blind because it is available only in printed form;

⁵⁴ when a disabled child is excluded from a school excursion because transportation means are not accessible;

limited (*restriction*)⁵⁵. Discrimination can be direct⁵⁶ or indirect⁵⁷. Such behaviours may indeed "impair or nullify the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field". Also denial of reasonable accommodation is considered as a form of discrimination⁵⁸.

Another important concept related to discrimination of persons with disabilities is equalization of opportunities, mentioned in art. 5 of the UN Convention and precisely defined in the Standard Rules of the United Nations⁵⁹. Appropriate measures and support mechanisms must be introduced to guarantee equalization of opportunities on an equal footing with other citizens, thus enabling persons with disabilities to take full part in the life of the community and enjoy all human rights and fundamental freedoms.

Non-discrimination and equalization of opportunities together, as the international legal framework of reference, entail that all States and societies take action to eliminate, with reasonable accommodation, existing violations.

Protection of human rights of persons with disabilities applies to a wide range of rights and activities: from access to goods and services, to protection of sensitive data and medical and social treatments.

In the framework of the protection of these rights, the CSB believes that difficulties in accessing health services are a major violation of the principle of justice and equality of treatment⁶⁰. In consideration of the above, the CSB considers general practitioners and/or

⁵⁵ when architectural barriers limit access to some services of a public facility;

⁵⁶ when the blind and the deaf are excluded from staff recruitment;

⁵⁷ when competitions or exams take place in the upper floors of a building without elevator.

⁵⁸ "Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms". The most significant example in Italy is the increase in the number of pupils per classroom which, for economic reasons, alters the ratio between students and students with disabilities set by law. This measure cancels a solution aimed at guaranteeing due educational attention to these students ("reasonable accommodation") and can be considered, therefore, a violation of human rights. It is not by chance that the Italian Constitutional Court in its decision 80/2010, referring to art. 3 of the Italian Constitution and to the UN Convention, stressed that expenditure cuts in education cannot be made in an equal manner for all students. Students requiring greater support must be considered according to different parameters and adequate educational support must be guaranteed. Consequently, the Italian 2008 budget law, which had introduced some cuts in education, had to be amended so as to introduce an ad-hoc assessment of these students, who must be granted a right to study with adequate support.

⁵⁹ The Italian translation of the Standard Rules, translated by DPI Italia Onlus, can be downloaded from the website www.arpnet.it/ahs/NU93-NORMEDIS.htm

⁶⁰ Indeed, it often happens that many health services are in facilities with architectural barriers, which rarely have easily accessible technological equipment (such as CAT or X-ray machines). Moreover, according to a sectoral approach to functional diversities, persons with disabilities are directed to specialists. The latter are considered the only competent professionals able to intervene, while general practitioners and paediatricians, who could provide on-going assistance for the aspects of their competence, are bypassed, also for the management of conditions linked to functional disability.

paediatricians of one's choosing as the professionals who, on a priority basis, can play a fundamental role in assisting persons with disabilities and their families by providing them with continued support as for therapeutic choices and behaviours related to personal development.

A NEW IDEA OF JUSTICE FOR PERSONS WITH DISABILITIES

In the literature dedicated to persons with disabilities (and also in disability studies) the concepts of justice underlying the different disability models have often been disregarded. This has hindered the coherent implementation of social and legislative changes inherent in each model.

As a matter of fact, each disability model has produced a different idea of justice for persons with disabilities and consequently influenced policies implemented in local communities.

A **value-based model**, typical of the Greek and Roman society, attributing persons with disabilities very poor values, corresponds to an idea of justice which in modern times resulted into the Nazi practices of active euthanasia and the utilitarian theory, according to which persons with disabilities are a heavy burden for families and society and, as such, can be suppressed. Such theories risk to include increasingly wider groups of population (patients affected by rare diseases, babies born before term, people in vegetative state), who would not benefit from progresses of biomedical sciences.

The **charity model of disability**, which, though originating in the Middle Ages, is still present in some contemporary social and cultural contexts, linked the condition of persons with disabilities to a context of poverty, family abandonment and social fragility. According to this model of disability, the concept of justice was based on divine retribution after death and led to the creation of charity institutes, often residential structures, welcoming these people. The initial charity approach was then flanked by a segregation practice of social exclusion and self-complacency of these institutions, whereby interested people were heavily stigmatised by society and became undesirable.

The **production/performance model** introduced by the industrial revolution, based on the idea of people able to work, excluded by principle "ill" and "unable" people, which in all case were considered unproductive. The idea of justice for people with disabilities in this model justified the choice of isolating these persons from the rest of society by placing them in special and separated institutes. Indeed, they were not considered able to live and work as members of the community. Today's cultural resistance by companies to accept the quota system obliging them to employ a certain percentage of workers with disabilities derives from this prejudice. Over the last years, the development of support measures to facilitate employment inclusion has enabled competent people to work profitably in a workplace suitable to their abilities.

In the **medical model** persons with disabilities are considered affected by a disease and as such, in order to recover lost functionality, they only require health rehabilitation treatments. As a matter of fact, for many persons with disabilities, medical care may make the impairment situation stable and thus chronic. In these cases, medical treatments should be proportionate to the real advantage the interested person may obtain. Therefore, instead of granting intensive

rehabilitation treatments, maintenance treatments should be guaranteed. This approach has often relegated persons with disabilities in medical rehabilitation institutes for whole their lives.

Moreover, as underlined by art. 26 of the Convention⁶¹, in case of chronic conditions (physical, sensory, mental or intellectual impairment), habilitation services should be offered, since these do not aim at the elimination of the conditions linked to functional diversity - an objective often impossible to achieve - but work on the *empowerment* of people, on their abilities, considering the features of each person⁶².

It is evident that the idea of justice linked to this model has led over time to mainly medical solutions which, besides being ineffective in case of people with permanent functional diversities, are often expensive, thus using resources which could be destined to other forms of support often more appropriate.

The **welfare/protective model** of disability, combining the elements of the various models expressed above, defines persons with disabilities as subjects that can benefit only from various forms of welfare, because they are unable to work. It is a model that is based on a tautological thesis, because on one hand it recognizes, by assumption, the incapacity of persons with disabilities to live in society, on the other, just because they are recipients only of welfare solutions, these persons are impoverished in their individual and social capacity. According to the idea of justice of this model, these people should benefit from state support measures only in periods of economic prosperity, when there is a surplus of resources, otherwise they are considered an economic burden for society. The contradiction in this concept of justice is that welfare measures are in any case an unproductive cost, for some a sort of "social parasitism"; moreover no consideration is given to the fact that disability affects a growing number of people since, on account of the improved living conditions, life expectancy has increased considerably since a few years ago⁶³.

⁶¹ Convention on the Rights of Persons with Disabilities, art.26 - Habilitation and rehabilitation: *1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes: 8a) begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths; (b) support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.*
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

⁶² For example, instead of proposing to a paraplegic person in a wheelchair, rehabilitation treatments to recover the standing balance, with performances often far from the original ones, it would be more appropriate to adequately support his/her ability to use a wheelchair.

⁶³ Think of people affected by the Down syndrome or with tetraplegia caused by spinal cord lesions.

The **compensation model** of disability was developed following the requests for safeguarding millions of workers injured on the workplace or following the request for compensation of the veterans that had fought in the first world war and had come back to their homeland injured and/or with permanent functional limitations. The need to evaluate the level of damage suffered by these persons to compensate them with corresponding benefits, gave birth to – first within insurance practices, then broadened to the whole system of verification linked to benefits foreseen by welfare – the system of parameters and tables of evaluation of invalidity. In fact, constructed according to the value attributed to an anatomical loss or an acquired disease, these systems of evaluation have contributed to stigmatizing persons with disabilities, by assigning them different rates of invalidity. The idea of justice that is behind this approach is based on the recognition of a damage suffered in the exercise of a task that is socially recognized (working for a company, combating for their homeland), with the aim of assigning to the person who suffered damages a monetary compensation corresponding to the seriousness of the damage suffered. This setting further contributed to stigmatizing the condition of persons with disabilities, mainly when the checking systems were used also to evaluate the assigning of the welfare benefits: a person evaluated with a 100% invalidity is assessed as unemployable, to be included in the rehabilitative-welfare circuit. This approach reduces the person to a characteristic, to his/her functional limitation, and does not consider him/her as a human being.

All these models of disability are intertwined and combined, producing a negative vision of the condition of persons with disabilities, to whom it is subjectively attributed – for their medical condition and social fragility – the responsibility for not being able to be part of society. It is not by chance that when some persons with disabilities manage to live a full life they become extraordinary persons, almost similar to heroes.

In the last decades, models of disability that highlighted the responsibility of society for persons' condition of disability were elaborated.

The first example is the **social model** of disability.⁶⁴ Born in the United Kingdom in the 1970's, it was subsequently applied by the Anglo Saxon world and progressively influenced all countries. This model starts from the criticism of the medical model of disability, highlighting the responsibility of society in disabling the persons who have needs to move themselves, direct themselves, communicate and interact in a different way. The idea of justice that accompanies this vision demands that the states and society remove the obstacles and barriers that prevent the participation of persons with disabilities and the equality of conditions. The limits of this approach, developed in contrast to the medical model of disability, are to be found in an underestimation of other elements important for the assessment. However, this model has deeply influenced persons

⁶⁴ Oliver M. *Politics of Disablement*. Macmillan, London 1990; Oliver M.: *Understanding disability. From theory to practice*. New York, 1996. Palacio A., Romanach J. (1990) *El modelo de la diversidad. La bioética y los Derechos Humanos como herramientas para alcanzar la plena dignidad en la diversidad funcional*. Presentación de R. De Asís Roig. (Santiago de Compostela), Edición Diversitas-AIES.

with disabilities and their organizations and strengthened their commitment to build inclusive societies, where all people can live in equal opportunities⁶⁵.

On the basis of the debate originated from this model, as indicated in the paragraph on the evolution of models of disability, WHO developed the ICDH (1980)⁶⁶, the first model of disability anchored to medical determinism, and subsequently, on the basis of the Standard Rules, the ICF (2001)⁶⁷, which tried to eliminate the exaggerations of the social model by introducing the **bio-psychosocial model** of disability. As a matter of fact, ICF is both a nosography applicable to all human beings to measure their health conditions and a model of disability. By stressing the fact that disability is a sort of "umbrella" including interdependent factors, this model highlights interconnections existing between people's health conditions and external factors (mainly environmental ones), which may favour or hinder their participation in society. Also according to this model, which intends to combine the medical and the social models by including personal psychological factors, the concept of justice points at the responsibilities of society in determining disability conditions. However, despite all limitations mentioned, ICF has the merit to be an effective instrument to the extent it changed the views of many health care and social professionals.

Generally speaking, one could say that the idea of justice at the basis of the disability models preceding the bio-psychosocial one, which is focused on human rights, and all related policies and services, is still largely centred on medical and rehabilitation services, welfare services or other mechanisms based on compensation or protection. Indeed, such policies are often defined as welfare or social protection policies.

⁶⁵ This approach also influenced the United Nations in 1993 when approving the *Standard Rules on the equalization of opportunities for persons with disabilities* (<http://www.un.org/esa/socdev/enable/dissre00.htm>)

⁶⁶ *International Classification of Impairment, Disability and Handicap*.

⁶⁷ *International Classification of Functioning, Disability and Health* (<http://www.who.int/classifications/icf/en/>)

THE IDEA OF JUSTICE IN THE MODEL OF DISABILITY BASED ON RESPECT FOR HUMAN RIGHTS

The Convention on the Rights of Persons with Disabilities, even if not in an explicit manner, introduces a new model of disability based on the respect for human rights. This model re-elaborates the social model, framing it in a universalistic perspective, based on the approach centred on rights. This model, already widely described in the previous chapters, transforms the economic, political and social behaviours linked to persons with disabilities⁶⁸.

Indeed, at the basis of the Convention is a new model of justice. No longer a metaphysical justice, nor a justice based on welfare and treatment, not even a concept of justice based exclusively on compensation or protection. The new paradigm, based on equality and non-discrimination, on the enhancement of human diversities, on the empowerment of discriminated and disadvantaged persons, requires the elimination of obstacles and discriminations, adequate support to people and the granting of services and benefits aimed at the inclusion of marginalized subjects.

In other words, we are going from a welfare system based on social protection to a welfare system based on social inclusion. This means that the evaluation of the capacity of persons with disabilities should not be limited to percentage parameters, but concentrate on the real conditions

⁶⁸ Some useful elements for the new approach to disability come from Amartia Sen's considerations, who has drawn attention to the concept of capability also applied to persons with disabilities (capability is an activity that is included in the concept of empowerment mentioned above) or different heuristic instruments in defining plans of action targeted to persons with intellectual disability, as narrative medicine proposes, overcoming an exclusively medical approach. See Sen, A. (1992) *Inequality Reexamined* Cambridge, 1992; Sen, A. (1999) *Development As Freedom*, New York, 1999; Sen, A. (2005) *Human Rights and Capabilities*, Journal of Human Development 6, no. 2. 151-166; Sen, A. (1979) *Utilitarianism and Welfarism*, The Journal of Philosophy, LXXVI (1979), 463-489; Sen, A. (1985) *Commodities and Capabilities*, Oxford, 1985; Sen, A. (1999) *Development As Freedom*, New York, 1999. See also: Nussbaum, M. C. and Sen, A. (1993) *The Quality of Life*, Oxford, 1993; Nussbaum, M. C. 2003 *Capabilities as Fundamental Entitlements: Sen and Social Justice*, Feminist Economics 9(2/3): 33–59; Nussbaum, M. C. (2000) *Women and Human Development: The Capabilities Approach*, Cambridge, 2000; Biggeri, M, Bellanca N, Tanzj L. e Bonfanti S, *Sulle politiche per le persone con disabilità: il progetto di vita e la strategia a mosaico* in Biggeri M. e Bellanca N. (by) *Dalla relazione di cura alla relazione di prossimità. L'approccio delle capability alle persone con disabilità*, Liguori, Naples, 2010, pages 165-187; Biggeri M. e Bellanca N., *Ripensare le politiche sulla disabilità in Toscana attraverso l'approccio delle capability di Amartya Sen: from cure to care, Rapporto finale*, Regione Toscana, 2010; Biggeri M. e Bellanca N. (by) *L'approccio delle capability applicato alla disabilità: dalla teoria dello Sviluppo Umano alla pratica*, Dossier n° 3 Umanamente, UCODEP, Arezzo, 2011.

See the monographic number of Alter. European Journal of Disability Research, vol. 5, n°3, July/September 2011, *The "Capability Approach" to rethink policies for persons with disabilities*. In particular, Barbuto R., Biggeri M., Griffo G., *Life project, peer counselling and self-help group as tools to expand capability, agency and human rights in Alter*, European journal of disability research, vol. 5, n°3, July/September 2011, pp.192-205; Ruggerini C, Griffo G, Manzotti S (2009), *Empowerment, famiglie, persone con disabilità intellettiva: modi nuovi di "prendersi cura"* Servizi Sociali. Number 2: 45- 48, 2009; Ruggerini C, Vezzosi F, Solmi A, Manzotti S (2008), *Narrative Medicine in Genetic Syndrome with Intellectual Disability* In A Verri (Ed.), *Life Span Development in Genetic Disorders – Behavioral and Neurobiological Aspects*. New York, 2008; Ruggerini C, Vezzosi F, Dalla Vecchia A (2008), *Prendersi cura della disabilità intellettiva – Coordinate OMS, buone prassi, storie di vita*. Trento, 2008; Ruggerini C., Manzotti S., Griffo G., Veglia F. *Narrazione e disabilità intellettiva. Valorizzare le esperienze individuali nei percorsi educativi e di cura* Trento, ed. Erickson, 2013.

and potentialities of people; the interventions should not be of a generic welfare nature, but aimed at removing barriers and obstacles and supporting people in achieving autonomy and social inclusion; the policies should address and guarantee support to persons with disabilities not only in the health and welfare area, but also in sectors such as labour, education, transport, constructed areas, and so on.

The justice model linked to the Convention profoundly changes the political interpretation of the condition of persons with disabilities, who are no longer persons made vulnerable by a functional impairment, but citizens entitled to the enjoyment of their rights, to whom society must give answers in terms of equality of opportunities and non-discrimination.

The Convention considers persons with disabilities part of society and therefore beneficiaries of all policies and programmes. This vision, respectful of human rights, to which all citizens are entitled, obliges the states to consider persons with disabilities in all measures, legislations and policies. This means that the resources, that were previously destined to some citizens, to which were added, in prosperous times, resources for persons with disabilities (and other social “vulnerable” groups), must be used for all citizens⁶⁹. The innovative approach of this vision relates to the policies of mainstreaming, according to which citizens with disabilities pass from the role of assisted persons to that of potential contributors, who need adequate support to participate in the life of the community. This will also entail a different collection of statistical data, in order to take account of the impact of the inclusion policies⁷⁰. Therefore, data to be processed shall include, for example, the level of accessibility of a city, the discriminations ascertained in the access to goods and services, the obstacles and barriers that prevent full participation and inclusion in sectors such as education, work, tourism and free time...

The CSB is well aware that, in order to develop these new policies and implement the new idea of justice linked to Convention, it is necessary to acquire new knowledge and competences, new cultural approaches, where the role of persons with disabilities or of their families, when they cannot represent themselves, is fundamental.

⁶⁹ In this framework, also the types of services and benefits should be changed: from interventions destined to custody and assistance to support for community life, from institutionalization policies to services for independent living (art. 19 of the CRPD), from prescription of devices based on pathologies to allocation of assistive devices based on the right to personal mobility and autonomy (art. 20 of the CRPD).

⁷⁰ See the results of the European project EuRade, promoted by the European Disability Forum and the University of Leeds. Indeed, in the final report of the project it is highlighted that in the area of disability it is important to move from a traditional research method based on medical prevention of diseases (on which till yesterday European research programmes were based) to a research method focusing on the removal of obstacles and barriers, technologies oriented to autonomy and self-determination, policies of support for full participation in the social life of persons with disabilities.

BIOETHICS AND PERSONS WITH DISABILITIES

The CSB takes note of the growing concern of some international associations of persons with disabilities and their families for the additional risks of discrimination and violation of human rights against persons with disabilities deriving from some practices related to the progress made in biomedicine and genetics.

With reference to this issue, many initiatives have been carried out, starting from those promoted by *Inclusion International*⁷¹ which, in 1995 worked on the UNESCO Convention on Human Genome⁷², and by the *Disabled Peoples' International*⁷³ - European Region, which, in 2000, organised a world seminar on "Bioethics and human rights of persons with disabilities" and issued a reference document on the risks of discrimination which may derive from biomedical practices⁷⁴. Subsequently, many other positions were expressed underlying the risk of violation of human rights in the framework of biomedicine⁷⁵.

The CSB underlines how, over the last years, in various countries, the activities related to biomedicine have concerned persons with disabilities. The discriminatory methods used have caused a strong emotional impact on public opinion, since the issues at stake are people's quality of life, their right to live (euthanasia, right to life) and the possibility to determine the form and characteristics of human beings (assisted procreation, genetic therapies, genetic manipulation, cloning). For the first time ever, science has almost acquired the powers allowing nature to "create" and "transform" life, with the justification that it can prevent and overcome diseases and infirmity, enhance mankind, strengthen reproductive capacities beyond the limits posed by age and the choice of the partner.

⁷¹ World Federation of families of persons with disabilities.

⁷² Protection of dignity and human rights. Answer to the 1995 draft Declaration of the International Council on Bioethics of UNESCO, September 1995, on human genome and modifications, drafted by Inclusion International (January 1996)

⁷³ International association working in favour of the protection of the human rights of persons with disabilities, represented in 142 countries all over the world.

⁷⁴ The Conference "Bioethics and human rights of persons with disabilities" was held in Solihull (Great Britain) on 12-13 February 2000. In the context of this Conference the Declaration entitled "The right to live and be different" was adopted. The following document resulted from a project financed by the European Commission: Disabled people speak on the new genetics. DPI Europe position statement on Bioethics and Human Rights (2000) (www.dpi-europe.org/past_editos/bioethics_issues/)

⁷⁵ See, just to mention the most important ones, the activity of the International Federation for hydrocephalus and spina bifida, with the Resolution on prenatal diagnosis and the right to be different (Toulouse 2000), the Resolution on euthanasia of new-borns affected by spina bifida and/or hydrocephalus (Helsinki 2006), Groningen Protocol. Position Paper on the Disability Stereotypes, International Human Rights and Infanticide (by James E. Wilkinson 2008), documents downloadable from www.ifglobal.org/en/human-rights.html See the activity of the European Disability Forum with the Resolution on prenatal diagnosis and the right to be different (Athens 2001), Resolution on active termination of life of new-born children with disabilities and the right to life (Rome, 2006), documents downloadable from <http://www.edf-feph.org/>.

The concerns of the associations of persons with disabilities and their families derive from considerations on the risk of using the "medical model" of disability as reference cultural approach to biomedicine and new genetics. Also the World Health Organization, in approving ICF, underlined the distortions that may derive from a prejudicial view of persons with disabilities. The UN Convention offers a new approach to disability, based on respect for human rights, which bioethics should use as a starting point and to enrich.

In the context of such shared considerations, the CSB recognises the great contribution given to society by scientific progress in general, and by the discoveries in medicine, in particular, which have enabled many persons with disabilities to live and be treated. The CSB is of the opinion that scientific development should be promoted and supported.

However, the CSB deems it fundamental that research be directed to the improvement of the quality of life of all people and not to deny, to some people, the right to live and enjoy rights, goods and services⁷⁶.

The CSB shares the concern of the associations of people with disabilities that modern genetics may turn into eugenics, should the affirmation of the idea, absent in nature, of a perfect human being prevail. In this context, illness, pain and diversity would be considered imperfections to be eliminated and not as conditions that all people may experience over the course of their life. As a matter of fact, imperfections belong to mankind; they take various forms, and, as stated in Art. 3 of the UN Convention, functional diversity is only one of these.

Indeed, the idea of a perfect man, with no genetic defects, imperfections, diseases belongs to a modern mythology. People are the sum of abilities and limitations, potentialities and competences, which, on the basis of life experiences, of learning processes, of challenges faced to reach objectives or fulfil desires, form all human beings in their constant evolution⁷⁷. In other words, each human being has his/her functioning. Moreover, the post-human⁷⁸ approach highlights how the human being is increasingly considered as a cyborg, where the natural part is combined with the artificial one. In this context, attention is focused on performance and availability of devices and technologies at disposal of all human beings.

⁷⁶ For example, think of access to medical treatments by premature babies, of non-discrimination in the compilation of the organ transplant lists, of the right to benefit from medical treatments on an equal footing with the other citizens in developing countries.

⁷⁷ Nussbaum, M. (2001). *Divenire persona*. Bologna, 2001.

⁷⁸ Marchesini, R., 2002, *Post-human. Verso nuovi modelli di esistenza*, Torino, Bollati Boringhieri; Halberstam, J., Livingston, I., a cura, 1995, *Posthuman Bodies*, Bloomington, Indiana UP; Longo, G. O., 2003, *Il simbiote. Prove di umanità futura*, Roma, Meltemi; Haraway, D. J., 1991, "A Cyborg Manifesto. Science, Technology, and Socialist-Feminism in the Late Twentieth Century", in *Simians, Cyborgs and Women. The Reinvention of Nature*, London, Routledge; trad. it. 1995, "Un manifesto per cyborg. Scienza, tecnologia e femminismo socialista nel tardo ventesimo secolo", in *Manifesto Cyborg. Donne, tecnologie e biopolitiche del corpo*, Milan, Feltrinelli.

EXAMPLES OF VIOLATIONS OF HUMAN RIGHTS OF PERSONS WITH DISABILITIES IN THE LIGHT OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The CSB has considered it appropriate to include in its reflection an analysis of some examples of violations of the human rights of persons with disabilities, based on different bioethical approaches, in the light of the principles embodied in the Convention on the Rights of Persons with Disabilities.

Aware of the complexity of each issue referring to individual cases that would constitute the topic of a specific document, the CSB wants to give some examples only to outline the different bioethical situations in the framework of values guaranteed in the Convention.

PRENATAL TESTING AND GENETIC COUNSELLING

Many countries allow abortion in their legislation. The theme, which does not involve San Marino, where abortion is expressly prohibited by law, concerns many bioethical aspects relating to persons with disabilities.

Pregnancy is increasingly associated with significant health risks to the mother and the foetus. The forms of protection for this period of women's lives are almost always related to health. This approach contributes substantially to the perception that pregnancy poses health risks and the baby must be healthy. For this reason, prenatal diagnosis has become a well-established practice, and generates family, medical and social expectations. In other words, all tests prior to delivery shall be aimed at identifying any malformation that the foetus might have, allowing a mother, through special legislation, to terminate pregnancy for a therapeutic abortion. The concept of malformation (present in many national legislations) is extremely general and arbitrary and discriminatory in many respects, since it covers a variety of situations including different mental and physical conditions.

Actually, such intervention is not for the foetus (who is not treated, but eliminated), but probably for society, which eliminates someone who is not welcome. The discriminatory element is clear: although diagnosis can be accurate (tests do not always ensure a precise diagnosis), the information provided to parents is almost always oriented, since it is based on a medical opinion regardless of the kind of functional diversity the soon-to-be-born baby may have. In this context, the information provided to the couple (often given in few minutes) is already oriented, because it is provided exclusively in a medical context, without any other information allowing to have a comprehensive and realistic view of the future living conditions of the foetus. Proper and comprehensive counselling should also include the presence of parents and/or members of

associations, who are qualified and trained to deal with that particular type of functional diversity⁷⁹.

In this context, the articles of reference in the Convention are the following:

Article 10 - Right to life

Article 25 - Health - Paragraph 1, letters a), b) and d)

EUTHANASIA

For more than 10 years a debate has been carried out on an international level to limit the right to life of persons with disabilities having important functional diversities. The possibility of carrying out prenatal screening and postnatal tests to obtain a series of information on the characteristics of the foetus and to timely diagnose some functional diversities has led philosophers and scientists to wonder about the possibility of limiting the right to life of persons with disabilities.

The first negative judgements have been expressed by Peter Singer⁸⁰, an American moral philosopher, who has stressed that in case of limited resources, a choice must be made on the people to whom social and health measures are to be applied. Therefore, persons with important functional limitations should be eliminated, since they entail unproductive costs and are a burden to society and their families. This position has also been reflected in the Groningen Protocol (The Netherlands)⁸¹, in which some practitioners stressed the necessity to end the life of persons with important functional diversities caused by spina bifida. Something similar has also happened in the United Kingdom, where the Royal College of Obstetricians and Gynaecology requested Nuffield Council on Bioethics to be authorised to end the life of new-born babies with important functional diversities⁸². In both cases, the reasons reflect Peter Singer's approach, which is similar to that one

⁷⁹ Barbuto R, Ferrarese V, Griffio G, Napoletano E, Spinoso G *Consulenza alla pari (da vittime della storia a protagonisti della vita)*; Comunità Edizioni, 2006.

⁸⁰ Singer P., *Scritti su una vita etica*, Il Saggiatore, Milan 2004; Singer P., *Practical ethics*, Cambridge University Press, Cambridge 1993 (Italian translation, *Etica pratica*, Liguori, Naples 1989); Singer P., *La vita come si dovrebbe*, Il Saggiatore, Milan 2003.

⁸¹ Verhagen E, Sauer P. "The Groningen Protocol—Euthanasia in Severely Ill Newborns." *New England Journal of Medicine* 2005; 352(10):959-62. 2 Beddies T, Schmiedebach HP. "'Euthanasie'—Opfer und Versuchsobjekte. Kranke und behinderte Kinder in Berlin während des Zweiten Weltkriegs." [*'Euthanasia'—victims and test subjects. The fate of diseased, disabled children in Berlin during World War II*]. *Medizinhist J* 2004; 39(2-3):165-96. For the protocol, see the website: http://cbhd.org/resources/endoflife/beals_2005-03-24_print.htm See also the websites: www.cbhd.org/resources/endoflife/beals_2005-03-24.htm#2 and www.cbhd.org/resources/endoflife/beals_2005-03-24.htm#1

⁸² The issue raised by the Royal College of Obstetricians and Gynaecology was the following: "Senior doctors are urging health professionals to consider permitting the euthanasia of seriously disabled new-born babies. The college is arguing for "active euthanasia" to be considered for the overall good of parents, sparing them the emotional burden and financial hardship of bringing up the sickest babies". The answer provided by the Nuffield Council on Bioethics was negative.

taken by Nazism when 250,000 persons with different disabilities were exterminated through Aktion T4⁸³. Even though in the cases mentioned above no explicit reference is made to a eugenic approach, such cultural approach emerges from the consideration that these lives are not worthy to be lived.

In this context, the articles of reference in the Convention are the following:

Article 10 - Right to life

Article 25 - Health - Paragraph 1, letters a), b) d) and f)

PREMATURE, LATE PRETERM AND PRETERM BABIES

During the last decades, technical and scientific progress has allowed the survival of new-borns of extremely low gestational age, in particular those born between 22 and 25 weeks, thus significantly overcoming the limit of 180 days specified in the Italian law on abortion (Law no. 194/78). The foetus was not thought to survive below that threshold.

Preterm births (about 10% of all deliveries) take place at low gestational ages for 1% of new-borns.

With the improvement of the survival rates of this category of new-borns an intense medical and bioethical dialogue has been carried out in several countries. This dialogue is mainly focused on the need to set out "guidelines" to guide and support healthcare professionals in their

⁸³ The bibliography on active euthanasia practices of the Nazi regime against persons with disabilities is vast. We only report texts in Italian: Paolini M.: *Ausmerzen*. Turin 2012; Horsinga Renno Mireille, *Una ragionevole strage*, Turin, Lindau, 2008; *La memoria degli altri, ebrei e disabili ricordano insieme*. Brochure of the event - 27 January 2008 International Holocaust Remembrance Day. Rome, Auditorium Parco della musica. Sala santa Cecilia. [Rome, s.n., 2008]; Barbuto Rita [and others], *Consulenza alla pari. Da vittime della storia a protagonisti della vita*. Comunità edizioni, 2006; Florida P.: *Tiergartenstrasse 4. Un giardino per Ofelia: dramma in due atti*. Naples, Filema, [2006]; TREGENZA M.: PURIFICARE E DISTRUGGERE I. IL PROGRAMMA "EUTANASIA". LE PRIME CAMERE A GAS NAZISTE E LO STERMINIO DEI DISABILI (1939-1941). VERONA, OMBRE CORTE, 2006; Hartmann Hinterhuber, *Uccisi e dimenticati. Crimini nazisti contro malati psichici e disabili del Nordtirolo e dell'Alto Adige*. Trento, Museo storico, 2003; Ricciardi von Platen Alice, *Il nazismo e l'eutanasia dei malati di mente*, Florence, Le Lettere, [2000]; BRUNNER H.: *Come un pescatore di perle*, Empoli, Hibiscos, 2001; LALLO A., TORRESINI L., *Psichiatria e nazismo*, Venice, Ediciclo, 2001; Friedlander H.: *Le origini del genocidio nazista. Dall'eutanasia alla soluzione finale*. Rome, Editori Riuniti, 1997; Goldhagen, D.J.: *I volenterosi carnefici di Hitler : i tedeschi comuni e l'Olocausto*. 3. ed. Milan, Mondadori, 1997; ZUCCOTTI S.: *L'olocausto in Italia*, foreword by Furio Colombo, Milan, TEA, 1995; PICCIOTTO-FARGION L.: *Il libro della memoria, gli ebrei deportati d'Italia (1943/1945)*, Milan, Mursia, 1991; CONSOLI M.: *Omocausto*, Milan, Kaos, 1971.

See also the following websites:

www.bbc.co.uk/ouch/fact/the_holocaust_and_disabled_people_faq_frequently_asked_questions.shtml;
www.ushmm.org/wlc/article.php?lang=en&ModuleId=10005200; en.wikipedia.org/wiki/T-4 Euthanasia Program;
www.aish.com/holocaust/people/My_Cousin_Karlchen.asp; forum.axishistory.com/viewtopic.php?t=45327;
forum.axishistory.com/viewtopic.php?p=406436&sid=bf18758337b16321164ffcd382a557aa#406436;
www.newstatesman.com/blogs/crips-column/2007/01/disabled-nazis-germany-program.

Articles on the topic can be found on the website of the Italian Federation for the Overcoming of Handicap (FISH):
www.superando.it

decisions concerning resuscitation treatment and the duration of intensive care provided to such new-borns, considering the high mortality rates at these gestational ages and the frequent neurological sequelae in survived babies. In Italy, the "Charter of Florence"⁸⁴, drawn up by a group of medical and legal professionals, has represented the first document issued for this purpose.

Subsequently, the Italian National Bioethics Committee (CNB) has reviewed critically the indications provided in the Charter of Florence for the different bioethical and legal implications deriving from it⁸⁵.

In particular, the Italian CNB has considered that *"the mere fact that the life of new-born infants, after the first resuscitation treatment, may continue with a handicap due to their prematurity and the brain damage that might in some cases be a consequence of this, does not demonstrate the futility (but at the most the limited usefulness) of the treatment."* It has also stressed that *"a treatment that prolongs the survival of a disabled person can never be defined futile, due to the simple fact that it is capable of prolonging his/her life, even if defined by some as being "of poor quality. (...) It is the Committee's opinion that the mere hypothesis of a disability, even serious, but compatible with life, destined to affect the premature baby cannot justify the withdrawal of treatment."*

Despite the different views of the Italian CNB members, the document issued intends to underline that the ethical principle on which the decisions shall be based is in "the child's best interest". However, this standard, which is often invoked in the bioethical debate, is not considered by all to be the best one or the easiest to interpret for the decision to take concerning neonatal care.

In a still very divisive bioethical debate on this issue, Freed's and his collaborators⁸⁶ declarations are topical, stressing the need not to succumb to the *"tyranny of the normal"*. In this regard, Robert⁸⁷ urged *"not to consider all disabilities unacceptable, since the ethical value of a society is expressed by the role that it assigns to the most vulnerable"*.

Also in this case, the approach based on respect for human rights introduced by the UN Convention does not connect the rights with the availability of economic resources or the attribution of a negative social stigma. On the contrary, it allows to respect the dignity of the person regardless of any characteristic he/she might have.

In this context, the articles of reference in the Convention are the following:

Article 10 - Right to life

⁸⁴ The Charter of Florence is published in "Rivista Italiana di Medicina Legale" 2006, XXVIII/1227-1246

⁸⁵ National Bioethics Committee: "Premature infants: Bioethical notes", 29 February 2008 (http://www.governo.it/bioetica/pareri_abstract/grandi_prematuri_29022008.pdf)

⁸⁶ Freed G.E., Hageman J.R.: "Ethical dilemmas in the prenatal, perinatal and neonatal periods", Clin Perinatol 1996, 23: 3

⁸⁷ Robert J.C.: "Le decision de fin de vie en period perinatale: un debat professional, une question de societe" Arch. Pediatr 2001, 8: 349.-351

Article 25 - Health - Paragraph 1, letters a), b) d) and f)

ENDING OF LIFE

The issue of ending of life for persons that suffer from severe disabilities⁸⁸ has become a topic in modern societies. The conditions of coma from traumas or accidents highlight how the progresses of medicine allow to keep alive persons who would have died in other periods of time.

The care and treatment of such persons need biomedical equipment, as well as hydration and artificial nutrition.

Some countries have approved legislations on active euthanasia⁸⁹. This issue, which is very sensitive and controversial, can be addressed correctly if it is put in relation with the different conceptions of quality of life and opportunities of support in the different societies. The different perceptions of persons with similar functional impairments with regard to their own dignity and quality of life depend on the existence of adequate family or social support measures.

In this context, the articles of reference in the Convention are the following:

Article 10 - Right to life

Article 25 - Health - Paragraph 1, letters a), b) d) and f)

INADEQUATE AND SEGREGATING TREATMENT

Segregating practices against persons with disabilities are still in place in many countries.

In Europe, more than 60% of students with disabilities⁹⁰ are forced to attend special schools in protected laboratories (nearly 500,000 people in Europe), in ad-hoc institutions and accommodation centres (about 500,000 in big institutions in addition to 2,500 places/beds and about 1.2 million in special facilities⁹¹).

⁸⁸ The national conference on disability held in Turin (2-3 October 2009) set up a working group on the issue "Vegetative states as paradigm of extreme disability". See the final document on the website of the Italian Ministry of Labour and Social Policies.

⁸⁹ Legislation on active euthanasia is in force in Switzerland and Holland and it is being discussed in France.

⁹⁰ Italy is the only country in the world where all students with disabilities, regardless of their type of functional diversity, have the right to attend ordinary classes in ordinary schools. In Germany, there are about 400,000 children with disabilities in special classes, 240,000 in France and 120,000 in the United Kingdom. In the 27 EU Member States (plus Switzerland) 60.9% of students with disabilities attending primary schools are segregated in special classes or schools (See the publication by the *European Agency for Development of Special Need in Education*:) "Special need education. Country data" published in 2008 (www.european-agency.org).

⁹¹ According to a European survey, there are 500,000 persons with disabilities segregated in in 2,500 large institutions in the 25 Member States www.community-living.info/

Segregation arises from the idea that such persons are not able to live in society or that they shall first be rehabilitated (often for their entire life) before having the right to live in the community.

In particular, the rehabilitation of persons needing psychiatric support takes place in psychiatric hospitals, where fundamental human rights are often violated. Indeed, in a 2007 seminar the UN High Commissioner for Human Rights⁹² reported that in these institutions human rights are constantly being violated, since abuses, violence, tortures and forms of inhuman and degrading treatment take place. Health and social services should be provided while promoting social inclusion and on an equal basis with all other citizens.

In this context, the articles of reference in the Convention are the following:

Article 19 - Living independently and being included in the community

Article 20 - Personal mobility

Article 28 - Adequate standard of living and social protection

EQUALITY OF TREATMENT AND ACCESS TO HEALTHCARE AND SOCIAL SERVICES

In developing countries, where limited resources lead to the exclusion of the persons considered to be the least useful for society, persons with disabilities are excluded from access to healthcare services. The access to health information and treatment services, such as those to fight AIDS/HIV or reproductive health services, is denied to persons with disabilities, thus creating a higher risk of infection from sexually transmitted diseases in persons that are unaware of the essential elements.

In industrialised countries there is an evident limitation of treatments that improve the health conditions of old people, who often are not self-sufficient on the basis of an unfavourable cost-benefit analysis.

The access to social and individual support services is directly related to the economic policies of States which, during economic crises, reduce welfare measures to avoid any waste. This has an impact on charity policies since they are possible only in periods of economic growth.

⁹² On 11 December 2007, the UN Office of the High Commissioner for Human Rights convened a meeting of a group of experts on "Freedom from torture, cruel, inhuman or degrading treatment or punishment and persons with disabilities". At the end of the meeting, the group of experts recognised that in total institutions the risk of violating the provisions of the Convention against torture and inhuman or degrading treatment is very high for persons with disabilities. See also the judgement of the European Court of Human Rights [*Grand Chamber, Case of Sytanev v. Bulgaria (application no. 36760/06) Judgement, Strasbourg 17 January 2012*], which ruled against the Bulgarian Government for the placement of a person suffering from schizophrenia in a social care home without ensuring the rights referred to in Articles 12 and 14 of the Convention on the Rights of Persons with Disabilities. See also Recommendation R(99)4 of the Committee of Ministers of the Council of Europe on the principles concerning the legal protection of incapable adults. Also the Council of Europe commissioners for human rights highlighted in their reports on the visits to Member States that human rights of persons with disabilities placed in public institutions are violated.

Starting from an approach based on human rights, the United Nations Human Rights Council approved a Resolution⁹³ stating that States have the moral duty to ensure, in periods of economic crisis, that even the most vulnerable groups be protected through continuous mainstreaming and equal opportunities policies to support their inclusions in all aspects of life.

A research activity carried out by FISH (Italian Federation for the Overcoming of Handicap) has shown that the services provided to persons with disabilities are organised in a way that violates the rights of persons with disabilities⁹⁴.

In this context, the articles of reference in the Convention are the following:

Article 25 - Health

Article 5 - Equality and non-discrimination

INTEGRITY OF THE PERSON

The integrity of persons with disabilities is a topic which is often ignored. This situation is illustrated by the case of an American child, Ashley, suffering from a rare cerebral disease, static encephalopathy. She needs intensive care and support because of a high dependence in everyday activities and of an intellectual disability. Ashley's parents, who are university professors, have requested and obtained from the competent Bioethics Committee of the hospital the authorisation to stop the growth of their child so that her organism could have moderate dimensions and be more easily managed. Healthcare professionals have removed Ashley's uterus and mammary glands that were forming. Subsequently, she has undergone hormonal treatment to prevent her from reaching puberty⁹⁵.

This case poses the problem of the prevailing interest: that of the person with disabilities or of the parents.

A similar example of discrimination can be found in the French legislation, under which it is possible, upon consent of parents, to sterilize women with intellectual disabilities living in total institutions⁹⁶.

⁹³ *Human Rights of Persons with Disabilities: National Frameworks for the Promotion and Protection of the Human rights of Persons with disabilities, Human Rights Council, 10th session, 26 March 2010.*

⁹⁴ Related FISH publication: *Final Report. MONITOR Project. Instruments to apply the UN Convention on the Rights of persons with disabilities.* L. 383/2000 letter f) – year 2009. [Rome, 2010]; *Study aimed at identifying, analysing and transferring good non-discrimination practices in the specific context of disability.* PON “Governance e Azioni di Sistema” - Obiettivo Convergenza, Asse D. Pari Opportunità e non discriminazione FSE 2007-2013. [Rome, 2010]; *Riconoscere e combattere la discriminazione delle persone con disabilità. Qualche istruzione per l'uso.* [Rome, 2008]. All FISH publications can be found at www.fishonlus.it/attivita/pubblicazioni/.

⁹⁵ Gunther D.F., Diekema D.S., *Attenuating Growth in Children With Profound Developmental Disability. A new Approach to an Old Dilemma.* Arch Pediatr Adolesc Med. 2006;160:1013-1017.

⁹⁶ Similar legislation is in force in Canada, in the United States and in Peru and it was in force in Japan, Sweden, Switzerland and in other countries. (http://fr.wikipedia.org/wiki/St%C3%A9rilisation_contrainte)

In this context, the articles of reference in the Convention are the following:

Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 16 - Freedom from exploitation, violence and abuse

Article 17 - Protecting the integrity of the person

INFORMED CONSENT

Therapeutic action and clinical trials require to provide the person undergoing treatment with all necessary and specific information so that he/she may freely decide, after having expressed free and informed consent. In relation to this issue, the associations of persons with disabilities stress the need that such consent be provided on the basis of clear and comprehensive information, especially in situations requiring to make particularly complex decisions. An example of this is prenatal genetic counselling. In this case, information concerning a possible functional diversity of the foetus is provided, in most cases, only by doctors, on the basis of instrumental analyses which, sometimes, are partially predictive and an exclusively scientific approach based on health assessment parameters. In order to allow a couple to provide an informed consent, the meeting should also be attended by representatives of associations of persons with disabilities or their parents. Such representatives, who shall be specifically trained on counselling⁹⁷, must be able to provide all the missing information and answer all the doubts and requests for clarification on the real future living conditions of the baby in case of functional diversities.

Another particularly complex situation is when informed consent is provided by persons with intellectual disabilities in relation to treatment in ordinary clinical practice or experimental practices. In this case, the bioethical approach requires to use all available instruments (predictive testing, support by experts in communication with these persons, activities to support self-determination) to ensure a consent reflecting the willingness of the person receiving information proportional to his/her understanding abilities, even if the consent may be provided by the legal representative.

The acquisition of such consent is particularly important from a bioethical point of view, when the incapacitated person has to participate in a clinical trial in developing countries or non-EU Member States which have not transposed relevant international rules into their national legislation. Indeed, such rules ensure the protection of incapable persons by obliging scientists to comply with specific requirements and the prior and mandatory approval on the part of ethics

⁹⁷ See note 78.

committees⁹⁸. Bioethical reflection in this sector is becoming more intense in consideration of the fact that clinical trials are increasing especially in countries lacking specific legislation⁹⁹.

In this context, the articles of reference in the Convention are the following:

Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 25 – Health

RESPECT FOR PRIVACY AND SEXUALITY

Segregating practices in institutions or places separate from society, hosting persons with disabilities who do not have any relatives taking care of them, and where rules and control applies, restricting their freedom of movement, outside and inside the institution, have negative effects on personal human rights, such as the right to sexuality. In these institutions, the possibility of having a sexual life is denied, because any support to sexual intercourses is regarded as incitement to prostitution¹⁰⁰. These are often persons living in institutions because they do not receive any adequate domestic support for independent living. However, they are capable of self-determination.

As regards the right to privacy, institutionalisation does not often ensure minimum levels of privacy. Such privacy is denied as far as space, furniture, self-determination, as well as management of personal time and needs are concerned¹⁰¹.

In this context, the articles of reference in the Convention are the following:

Article 22 - Respect for privacy

Article 23 - Respect for home and the family

⁹⁸ As far as the involvement of incapacitated persons in clinical trials is concerned, please see Italian Legislative Decree no. 211 of 24 June 2003 "Transposition of Directive 2001/20/EC relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use". Article 5 of the Directive "Clinical trials on incapacitated adults not able to give informed legal consent" sets out the conditions required to protect an incapacitated person in the event of his/her inclusion in a clinical trial.

⁹⁹ On this issue, see the recent Opinions of the Italian National Bioethics Committee: Pharmaceutical testing in developing countries, of 27 May 2011.

(http://www.governo.it/bioetica/pareri_abstract/Sperimentazione_paesi_in_via_sviluppo_27052011.pdf)

and Clinical trials on adults or minors not able to give informed consent in emergency situations, of 28 September 2012.

(http://www.governo.it/bioetica/pareri_abstract/Sperimentazione_clinica_pazienti_28092012.pdf)

¹⁰⁰ See on this issue the documents of the Conference *Dépendance physique: intimité et sexualité*, organised by the association *Coordination Handicap & Autonomie*, Strasbourg 27-28 April 2007.

¹⁰¹ De Rienzo E., De Figueiredo C. *Anni senza vita al Cottolengo. Il racconto e le proposte di due ex-ricoverati*. Rosemberg & Sellier, Turin 2000.

QUALITY OF LIFE

The main prejudice against persons with disabilities is the consideration that the quality of their life is worse than that of other persons because of their mental and physical condition. Quality of life cannot be assessed on the basis of parameters and generally recognised standards, but only on the basis of perceptions of the interested parties.

This is much more the case for persons with disabilities, for whom an external observer only assesses their disease or functional impairment. These prejudices are clamorously overcome by the paradox of disability¹⁰², since persons with serious and severe disabilities believe they live a life worth living. Actually, the quality of such persons' lives depend on the same conditions applying to all other people¹⁰³: the needs and rights of a person with disabilities are the same as those of a non-disabled person: these are physiologic and social needs, as well as needs for love, friendship, self-determination, self-esteem, self-realization, autonomy, etc... Therefore, they depend on the same conditions of all citizens: the economic condition of the family, possibility to study, to work, to be autonomous, to experience emotions and love and to enjoy self-determination as much as possible, etc.

The needs of every person peculiar are characterised by the means and instruments through which it is possible to meet them.

In this context, the articles of reference in the Convention are the following:

Article 5 - Equality and non-discrimination

Article 6 - Women with disabilities

Article 7 - Children with disabilities

Article 8 - Awareness-raising

REHABILITATION AND HABILITATION

The measures targeting persons with disabilities often do not go beyond medical and rehabilitation actions in developed countries. On the contrary, in developing countries, medical rehabilitation is often not included in basic health care services, as opposed to the indications provided by the WHO.

However, health care and rehabilitation measures are no longer effective when the condition of functional diversity stabilises and they must be replaced by adequate habilitation measures. If they are not replaced, rehabilitation measures may become inadequate and be a true prolongation of life by medical means. Indeed, habilitation is no more aimed at functional

¹⁰² Albrecht GL, Devlieger PJ. *The disability paradox: high quality of life against all odds.* (www.ncbi.nlm.nih.gov/pubmed/10390038)

¹⁰³ See speeches by Rita Barbuto, Generoso Di Benedetto, Lucia Lucchesi and Adriana Ciccio. "Bioethics and our life", documents of the Conference *Bioethics and disability*, organised in Solihull (Birmingham), 12-13 February 2000. See also the Solihull declaration annexed thereto.

recovery, which is no longer possible. It is focused on the functional diversity of the person and it is aimed at developing his/her adequate capabilities in order to enable the person to live an autonomous and self-determined life to the largest extent possible. Such objective can be achieved through empowerment actions, enhancement of available skills and expertise and use of adequate aids. Rehabilitation processes are mainly managed by healthcare professionals. Habilitation processes require multidisciplinary skills and in this case healthcare professionals often only perform counselling. If WHO estimates are confirmed, according to which 70% of the resources¹⁰⁴ of public health systems will be allocated to persons suffering from chronic diseases in the next years, it will be necessary to review public policies and services to achieve empowerment and social inclusion objectives.

In this context, the articles of reference in the Convention are the following:

Article 26 - Habilitation and rehabilitation

MULTIPLE DISCRIMINATION

Persons with disabilities are subject to discrimination. If they are women, children, migrants, old people, members of other religious and ethnic groups or persons with other sexual orientations, they might be subject to multiple discrimination. Indeed, in addition to disability there can be other conditions that are subject to discrimination. There can be an accumulation and, sometimes, an exponential growth of such other forms of discrimination. The risk of multiple discrimination becomes an aspect that, from a bioethical point of view, must be assessed with particular attention given the complexity and variability of the factors characterising it¹⁰⁵. Multiple discrimination especially affects women and children with disabilities, whose protection is covered by some specific articles of the Convention:

Article 5 - equality and non-discrimination

Article 6 - Women with disabilities

Article 7 - Children with disabilities

¹⁰⁴ World Health Organization. *The World health report: Health systems financing. The path to universal coverage*. Geneva, WHO, 2010.

¹⁰⁵ A survey carried out by the Italian Union against Muscular Dystrophy UILDM based in Rome has pointed out that in the city there are no accessible family advisory services (neither adequate places nor adequate instruments to carry out the required medical examinations) (http://www.consorzioparsifal.it/agenda/n3551_p1/roma-la-uildm-discute-di-sessualita-e-disabilita.html). See also World Health Organization, Department of Reproductive Health and Research- United Nations Population Fund (UNFPA). *Promoting sexual and reproductive health for persons with disabilities*. WHO/UNFPA guidance note. Geneva, WHO, 2009.

ETHICS AND PROFESSIONAL TRAINING BASED ON RESPECT FOR HUMAN RIGHTS

Training of professionals taking care of persons with disabilities should be updated on the basis of the principles and rules embodied in the Convention. The curricula of many professionals still lack training on disability (e.g. architects, engineers and all professionals dealing with construction and equipment can receive training on disability only by attending specific courses). Otherwise, such training is based on the medical/individual approach to disability (e.g. the sectors of medicine, law and services to the person). Also professional ethics and codes of conduct should focus on relations with persons with disabilities and their families.

The Convention insists particularly on this issue and the following articles deal with it:

Article 4 - General obligations - paragraph 1, letter (i)

Article 8 - Awareness-raising

Article 9 - Accessibility

Article 13 - Access to justice

Article 20 - Personal mobility

Article 24 - Education - paragraphs 1 and 4

Article 25 - Health

Article 26 - Habilitation and rehabilitation

PREVENTION OF DISABILITY

Under the Convention, States are required to reduce or eliminate conditions generating disability resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society. This approach identifies two important aspects of disability: the functional diversity of the person, which can be prevented through health measures (health information campaigns, health and medical-rehabilitation measures, vaccinations, etc.) and the elimination of obstacles, barriers and discriminations. This is accompanied by the support to the empowerment of persons' abilities, focusing particularly on inclusion measures and policies, based on equal opportunities and non-discrimination. Such new approach results in new treatment modalities, requiring health and social prevention.

In this context, the articles of reference in the Convention are the following:

Preamble letter (e)

Article 1 - Purpose

CONCLUSIONS AND RECOMMENDATIONS

Thinking about disability issues from a human rights perspective requires to review the bioethical approach to persons with disabilities. Furthermore, biomedical and technological advances should be aimed at ensuring adequate support to promote full citizenship and participation in society.

Indeed, as stressed by the WHO, disability is an ordinary condition of all human beings. Every person, during his/her life, will experience disability because of his/her age (e.g. the functional diversity of old people and children), of special biologic and social conditions (such as pregnancy, home or car accidents) and of certain health and social conditions.

The CSB notes that in the field of disability a cultural approach prevails which links the scarcity of resources to the opportunity not to invest in persons who are "ill, unable and unproductive" and do not ensure any social returns in terms of productivity. Such an approach violates the fundamental rights to life, health and justice.

If the respect for human rights is conditional on the availability of resources, there may be the risk that the beneficiaries of rights, services and opportunities are selected. If this happens, increasingly large groups of citizens may fall victim to such system.

The CSB wishes that the new cultural paradigm for the protection of the human rights of persons with disabilities can encourage a broad bioethical reflection, as well as an exchange of views among National Bioethics Committees, international bodies and professional associations involved together with the organisations that protect and promote the rights of persons with disabilities.

As regards persons with disabilities, on the basis of this document, the CSB considers it essential to comply with the following principles in the adoption of bioethical decisions and choices:

- **any decision regarding persons with disabilities shall be based on respect for their human rights, as defined in the UN Convention on the Rights of Persons with Disabilities (2006);**
- **the use of new discoveries in human genetics, in techniques and practices, shall be strictly regulated to prevent any discrimination and to fully protect, at any time, the Human Rights of persons with disabilities.**
- **Genetic counselling shall not be oriented, but based on rights. The information provided shall be widely and freely available and it shall reflect the real experience of disability.**
- **Parents shall not be pressured, formally or informally, to undergo prenatal tests or "therapeutic" abortion.**

- All children shall be welcome in the world and they shall be provided with adequate levels of social, practical and financial support.
- Human diversity shall be enhanced and not eliminated by means of discriminatory assessments on the quality of life, which lead to euthanasia, infanticide and death due to lack of measures.
- The organisations of persons with disabilities can be included in all those advisory and regulatory committees dealing with bioethical issues.
- Legislation shall be amended to put an end to discrimination based on disability as a legal ground for abortion.
- Training programmes for healthcare professionals and those dealing with bioethics shall be promoted. Such programmes shall be based on an approach respecting the human rights of persons with disabilities.
- No patent concerning genetic material shall be granted, because human genome is a common heritage of mankind.
- Medical treatment shall not violate the rights of persons with disabilities needing greater support for inclusion, while ensuring appropriate support to informed consent.
- The integrity of persons with disabilities shall be guaranteed under any condition.
- Rehabilitation and habilitation services shall be in place to provide persons with disabilities with adequate support for inclusion in society.
- All school facilities shall be adequately built to ensure access and inclusion of persons with disabilities.
- Healthcare professionals and medical and welfare staff shall be trained to provide persons with disabilities with accessible healthcare services covering the same range and having the same quality as healthcare services and programmes provided to other people.

GLOSSARY OF TERMS ON BIOETHICS AND DISABILITY

HABILITATION/REHABILITATION

With a view to ensuring that persons with disabilities fully enjoy all human rights and fundamental freedoms, it is necessary to adequately support them. Rehabilitation focuses on functional limitations and on the structures of the body to allow, through medical treatment, the recovery of the functionality of the damaged parts of the body. Focusing on the characteristics and abilities of persons, habilitation allows them to acquire skills in all spheres of life, even if such skills are developed differently. Persons with disabilities read with closed eyes, they move without walking, they communicate without speaking and live with an open heart. Society has forgotten these people and has designed services, goods and policies without considering persons with disabilities. The Convention underlines that States Parties "shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services". In the area of habilitation and rehabilitation, it is important to have access to assistance devices and technologies, to live independently, to be provided with personal mobility as essential human rights.

ACCESSIBILITY AND UNIVERSAL DESIGN

To offer equal opportunities, it is necessary to remove barriers and obstacles that hinder full participation in society. Accessibility means that all people shall have access to the "various societies, environments, as well as services, activities, information and documentation" (Standard Rules). Since disability belongs to the entire human race, society must design and plan all its activities and policies with the aim of including all citizens. The universal design approach allows to take into account the characteristics of all persons in a community and nation. Universal design means "the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" does not exclude assistive devices for particular groups of persons with disabilities where necessary" (Article 2).

DISABILITY

Disability is a social relationship between the characteristics of people and the extent to which society is able to take them into account. Disability is not a subjective condition of people, but depends on environmental, social and individual factors as the WHO 's ICF underlines. Disability is a condition that every person goes through over the course of their life (as a child, in old age and in various other situations) and it belongs to the entire human race. Disability is an evolving concept that needs to be considered in connection with the cultural and material conditions of each country (see Preamble point e) The definition of persons with disabilities is contained in the Convention (Article 1).

HUMAN DIVERSITY

The condition of disability is an experience that all human beings have lived, live and will live through. It is therefore important to consider disability as one of the features of human diversity. The history of negative cultural views and of the treatment that some characteristics of human beings have undergone over the centuries has given persons with disabilities a social stigma, these characteristics (and, therefore, all the people possessing them) with social undesirability. It is therefore important to include disability as one of the many differences that distinguish human beings, placing disability among the ordinary characteristics of human beings and removing the negative social stigma.

EQUAL OPPORTUNITIES

Being excluded and segregated, persons with disabilities do not have the same opportunity to choose as other people. Equal opportunities, according to the Standard Rules, means that "the needs of each and every individual are of equal importance" and that "all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation" in society.

SOCIAL IMPOVERISHMENT AND EMPOWERMENT

Disability is a cause and consequence of poverty. The differential treatment that persons with disabilities undergo has produced a social impoverishment in access to rights, goods and services that combines and often multiplies with economic poverty in a negative circle leading to social exclusion. For this reason, persons with disabilities represent almost half of the poor people in the world, given that more than 80% of these people live in developing countries (Preamble point t). In order to break this vicious circle, it is necessary to act both by changing society's approach to persons with disabilities and by working with these people for individual and social empowerment.

The United Nations global initiative against poverty, the Millennium Development Goals, should focus on persons with disabilities as a priority.

SOCIAL INCLUSION

In order to transform a society that excludes and discriminates, it is necessary to aim for the construction of inclusive societies, in which everyone can participate and contribute to the development of society. Inclusion is achieved without involving persons with disabilities. The path from exclusion to integration produces a presence in society of persons with disabilities who adapt to rules that have already been established by the community receiving them. Inclusion is a process that foresees that the included people have the same opportunities and decision-making powers as others on how to organise society. Inclusion is a right based on the full participation of

persons with disabilities in all aspects of life, on an equal footing with others, without discrimination, respecting dignity and enhancing diversity, through appropriate actions; overcoming of obstacles and prejudices and support based on mainstreaming.

MULTIPLE DISCRIMINATION

Discrimination affects people on the basis of characteristics that are subject to differential treatment, prejudice, obstacles and barriers to full participation in society. When such characteristics of gender, race, culture, religion, political opinion, age and disability are added together and combined between them, multiple discriminations which make the persons with such characteristics more vulnerable, are produced. A typical example are women with disabilities, who are subject to severe restrictions on access to rights, goods and services and social participation.

NON-DISCRIMINATION

The medical model of disability has brought about different approaches and treatment compared with other people, thus developing solutions and actions that impoverish persons with disabilities and cause continual violations of human rights. Indeed, all unjustified differential treatment is a violation of human rights. "Persons with disabilities [...] have the right to remain within their local communities" and to "receive the support they need within the ordinary structures of education, health, employment and social services" (Standard Rules). In order to combat this situation, anti-discrimination legislations have been created, which also protect persons with disabilities, prohibiting any discrimination based on disability through a legal basis that provides for the removal of discriminatory conditions using "reasonable accommodation" (Article 5).

Some countries have introduced anti-discrimination legislations at a national level (United States of America, Australia, New Zealand, Canada, United Kingdom), while the European Communities have introduced it at a regional level¹⁰⁶.

PARTICIPATION

The development of inclusive societies implies that the people included are protagonists of the process of inclusion, as experts on the way in which society must treat them. This means that persons with disabilities must be present with the same opportunities as other members of

¹⁰⁶ See Article 19 of the Treaty of Lisbon (2008). In the Charter of Fundamental Rights of the European Union (2000), which has become an essential annex to the Treaty of Lisbon, Article 21 makes specific reference to the various forms of discrimination: "Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited."

society in decisions, actions and plans concerning them. Therefore, the participation of people with disabilities and organisations representing them is a necessary methodology/action, based on the motto/right "**Nothing about us without us**".

INCLUSIVE DEVELOPMENT

Economic development theories consider the creation of a group of people excluded from the benefits of development to be a necessary consequence of this development. Development mechanisms are in fact often tied to conditions of disadvantage and unequal opportunities created by society itself. In the case of persons with disabilities, these conditions are found to be caused by mechanisms of discrimination and social exclusion that the United Nations Convention has made clear. Hence the need to promote inclusive development, which does not produce mechanisms of social and economic impoverishment, but guarantees all citizens the respect of their human rights.

INDEPENDENT LIVING

The obstacles and barriers, differential treatment and negative views concerning persons with disabilities, particularly those who cannot represent themselves or require complex assistance, have led in the past to the institutionalisation of such people. Actually, these people have the same human rights as everyone else and must be supported in their acquisition of autonomy, self-determination, independence and inter-independence. It was for this reason that the independent living movement arose, first in the United States of America at the end of the 1960s, and then throughout the world, through its own philosophy and appropriate solutions, such as centres for independent living, personal assistants, etc.

ANNEXES

UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES¹⁰⁷

Preamble

The States Parties to the present Convention,

(a) *Recalling* the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world,

(b) *Recognizing* that the United Nations, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind,

(c) *Reaffirming* the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination,

(d) *Recalling* the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Rights of the Child, and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families,

(e) *Recognizing* that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,

(f) *Recognizing* the importance of the principles and policy guidelines contained in the World Programme of Action concerning Disabled Persons and in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in influencing the promotion, formulation and evaluation of the policies, plans, programmes and actions at the national, regional and international levels to further equalize opportunities for persons with disabilities,

(g) *Emphasizing* the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development,

¹⁰⁷ <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>

(h) *Recognizing also* that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person,

(i) *Recognizing further* the diversity of persons with disabilities,

(j) *Recognizing* the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support,

(k) *Concerned* that, despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world,

(l) *Recognizing* the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries,

(m) *Recognizing* the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty,

(n) *Recognizing* the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,

(o) *Considering* that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them,

(p) *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,

(q) *Recognizing* that women and girls with disabilities are often at greater risk, both within and outside the home of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation,

(r) *Recognizing* that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child,

(s) *Emphasizing* the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities,

(t) *Highlighting* the fact that the majority of persons with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the negative impact of poverty on persons with disabilities,

(u) *Bearing in mind* that conditions of peace and security based on full respect for the purposes and principles contained in the Charter of the United Nations and observance of applicable human rights instruments are indispensable for the full protection of persons with disabilities, in particular during armed conflicts and foreign occupation,

(v) *Recognizing* the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms,

(w) *Realizing* that the individual, having duties to other individuals and to the community to which he or she belongs, is under a responsibility to strive for the promotion and observance of the rights recognized in the International Bill of Human Rights,

(x) *Convinced* that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities,

(y) *Convinced* that a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries,

Have agreed as follows:

Article 1: Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include 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.

Article 2: Definitions

For the purposes of the present Convention:

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

“Language” includes spoken and signed languages and other forms of non spoken languages;

“Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;

“Reasonable accommodation” means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

“Universal design” means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

Article 3: General principles

The principles of the present Convention shall be:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women;
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 4: General obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

(a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;

(b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;

(c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;

(d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;

(e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;

(f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;

(g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

(h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;

(i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.

2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with

disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

4. Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.

5. The provisions of the present Convention shall extend to all parts of federal states without any limitations or exceptions.

Article 5: Equality and non-discrimination

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Article 6: Women with disabilities

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

Article 7: Children with disabilities

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their

age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 8: Awareness-raising

1. States Parties undertake to adopt immediate, effective and appropriate measures:

(a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;

(b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;

(c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:

(a) Initiating and maintaining effective public awareness campaigns designed:

(i) To nurture receptiveness to the rights of persons with disabilities;(ii) To promote positive perceptions and greater social awareness towards persons with disabilities;(iii) To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;

(b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;

(c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;

(d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

Article 9: Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, 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. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

(a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;

(b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures to:

- (a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
- (b) Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
- (c) Provide training for stakeholders on accessibility issues facing persons with disabilities;
- (d) Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
- (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;
- (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;
- (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.

Article 10: Right to life

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

Article 11: Situations of risk and humanitarian emergencies

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

Article 12: Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Article 13: Access to justice

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their

effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Article 14: Liberty and security of the person

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:

(a) Enjoy the right to liberty and security of person;

(b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.

Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

Article 16: Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Article 17: Protecting the integrity of the person

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Article 18: Liberty of movement and nationality

1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:

(a) Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;

(b) Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;

(c) Are free to leave any country, including their own;

(d) Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country.

2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

Article 19: Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 20: Personal mobility

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

(a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;

(b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;

(c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;

(d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

Article 21: Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

(a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

(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;

(d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;

(e) Recognizing and promoting the use of sign languages.

Article 22: Respect for privacy

1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

Article 23: Respect for home and the family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

Article 24: Education

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:

(a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

(b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;

(c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

(a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

(b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

(c) Reasonable accommodation of the individual's requirements is provided;

(d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

(e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

(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;

(b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

(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.

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.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

Article 25: Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

In particular, States Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 26: Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
 - (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
 - (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Article 27: Work and employment

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

(b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;

(c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;

(d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;

(e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;

(f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;

(g) Employ persons with disabilities in the public sector;

(h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

(i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

(j) Promote the acquisition by persons with disabilities of work experience in the open labour market;

(k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

Article 28: Adequate standard of living and social protection

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

(a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;

(b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;

(c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;

(d) To ensure access by persons with disabilities to public housing programmes;

(e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

Article 29: Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:

(a) Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:

(i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;(ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;(iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;

b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:(i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties; (ii) Forming and joining

organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

Article 30: Participation in cultural life, recreation, leisure and sport

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:

(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.

2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.

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.

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:

(a) To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;

(b) To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;

(c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues;

(d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;

(e) To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

Article 31: Statistics and data collection

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

(a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;

(b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Article 32: International cooperation

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

(a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;

(b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;

(c) Facilitating cooperation in research and access to scientific and technical knowledge;

(d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

Article 33: National implementation and monitoring

1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination

mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

Article 34: Committee on the Rights of Persons with Disabilities

1. There shall be established a Committee on the Rights of Persons with Disabilities (hereafter referred to as “the Committee”), which shall carry out the functions hereinafter provided.

2. The Committee shall consist, at the time of entry into force of the present Convention, of twelve experts. After an additional sixty ratifications or accessions to the Convention, the membership of the Committee shall increase by six members, attaining a maximum number of eighteen members.

3. The members of the Committee shall serve in their personal capacity and shall be of high moral standing and recognized competence and experience in the field covered by the present Convention. When nominating their candidates, States Parties are invited to give due consideration to the provision set out in article 4.3 of the present Convention.

4. The members of the Committee shall be elected by States Parties, consideration being given to equitable geographical distribution, representation of the different forms of civilization and of the principal legal systems, balanced gender representation and participation of experts with disabilities.

5. The members of the Committee shall be elected by secret ballot from a list of persons nominated by the States Parties from among their nationals at meetings of the Conference of States Parties. At those meetings, for which two thirds of States Parties shall constitute a quorum, the persons elected to the Committee shall be those who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

6. The initial election shall be held no later than six months after the date of entry into force of the present Convention. At least four months before the date of each election, the Secretary-General of the United Nations shall address a letter to the States Parties inviting them to submit the nominations within two months. The Secretary-General shall subsequently prepare a list in alphabetical order of all persons thus nominated, indicating the State Parties which have nominated them, and shall submit it to the States Parties to the present Convention.

7. The members of the Committee shall be elected for a term of four years. They shall be eligible for re-election once. However, the term of six of the members elected at the first election shall expire at the end of two years; immediately after the first election, the names of these six members shall be chosen by lot by the chairperson of the meeting referred to in paragraph 5 of this article.

8. The election of the six additional members of the Committee shall be held on the occasion of regular elections, in accordance with the relevant provisions of this article.

9. If a member of the Committee dies or resigns or declares that for any other cause she or he can no longer perform her or his duties, the State Party which nominated the member shall appoint another expert possessing the qualifications and meeting the requirements set out in the relevant provisions of this article, to serve for the remainder of the term.

10. The Committee shall establish its own rules of procedure.

11. The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Convention, and shall convene its initial meeting.

12. With the approval of the General Assembly, the members of the Committee established under the present Convention shall receive emoluments from United Nations resources on such terms and conditions as the Assembly may decide, having regard to the importance of the Committee's responsibilities.

13. The members of the Committee shall be entitled to the facilities, privileges and immunities of experts on mission for the United Nations as laid down in the relevant sections of the Convention on the Privileges and Immunities of the United Nations.

Article 35: Reports by States Parties

1. Each State Party shall submit to the Committee, through the Secretary-General of the United Nations, a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned.

2. Thereafter, States Parties shall submit subsequent reports at least every four years and further whenever the Committee so requests.

3. The Committee shall decide any guidelines applicable to the content of the reports.

4. A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports, repeat information previously provided. When preparing reports to the Committee, States Parties are invited to consider doing so in an open and transparent process and to give due consideration to the provision set out in article 4.3 of the present Convention.

5. Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Convention.

Article 36: Consideration of reports

1. Each report shall be considered by the Committee, which shall make such suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the State Party concerned. The State Party may respond with any information it chooses to the

Committee. The Committee may request further information from States Parties relevant to the implementation of the present Convention.

2. If a State Party is significantly overdue in the submission of a report, the Committee may notify the State Party concerned of the need to examine the implementation of the present Convention in that State Party, on the basis of reliable information available to the Committee, if the relevant report is not submitted within three months following the notification. The Committee shall invite the State Party concerned to participate in such examination. Should the State Party respond by submitting the relevant report, the provisions of paragraph 1 of this article will apply.

3. The Secretary-General of the United Nations shall make available the reports to all States Parties.

4. States Parties shall make their reports widely available to the public in their own countries and facilitate access to the suggestions and general recommendations relating to these reports.

5. The Committee shall transmit, as it may consider appropriate, to the specialized agencies, funds and programmes of the United Nations, and other competent bodies, reports from States Parties in order to address a request or indication of a need for technical advice or assistance contained therein, along with the Committee's observations and recommendations, if any, on these requests or indications.

Article 37: Cooperation between States Parties and the Committee

1. Each State Party shall cooperate with the Committee and assist its members in the fulfilment of their mandate.

2. In its relationship with States Parties, the Committee shall give due consideration to ways and means of enhancing national capacities for the implementation of the present Convention, including through international cooperation.

Article 38: Relationship of the Committee with other bodies

In order to foster the effective implementation of the present Convention and to encourage international cooperation in the field covered by the present Convention:

(a) The specialized agencies and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their mandate.

The Committee may invite the specialized agencies and other competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates. The Committee may invite specialized agencies and other United Nations organs to submit reports on the implementation of the Convention in areas falling within the scope of their activities;

(b) The Committee, as it discharges its mandate, shall consult, as appropriate, other relevant bodies instituted by international human rights treaties, with a view to ensuring the consistency of

their respective reporting guidelines, suggestions and general recommendations, and avoiding duplication and overlap in the performance of their functions.

Article 39: Report of the Committee

The Committee shall report every two years to the General Assembly and to the Economic and Social Council on its activities, and may make suggestions and general recommendations based on the examination of reports and information received from the States Parties. Such suggestions and general recommendations shall be included in the report of the Committee together with comments, if any, from States Parties.

Article 40: Conference of States Parties

1. The States Parties shall meet regularly in a Conference of States Parties in order to consider any matter with regard to the implementation of the present Convention.
2. No later than six months after the entry into force of the present Convention, the Conference of the States Parties shall be convened by the Secretary-General of the United Nations. The subsequent meetings shall be convened by the Secretary-General of the United Nations biennially or upon the decision of the Conference of States Parties.

Article 41: Depositary

The Secretary-General of the United Nations shall be the depositary of the present Convention.

Article 42: Signature

The present Convention shall be open for signature by all States and by regional integration organizations at United Nations Headquarters in New York as of 30 March 2007.

Article 43: Consent to be bound

The present Convention shall be subject to ratification by signatory States and to formal confirmation by signatory regional integration organizations. It shall be open for accession by any State or regional integration organization which has not signed the Convention.

Article 44: Regional integration organizations

1. "Regional integration organization" shall mean an organization constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by this Convention. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by this Convention. Subsequently, they shall inform the depositary of any substantial modification in the extent of their competence.

2. References to “States Parties” in the present Convention shall apply to such organizations within the limits of their competence.

3. For the purposes of article 45, paragraph 1, and article 47, paragraphs 2 and 3, any instrument deposited by a regional integration organization shall not be counted.

4. Regional integration organizations, in matters within their competence, may exercise their right to vote in the Conference of States Parties, with a number of votes equal to the number of their member States that are Parties to this Convention. Such an organization shall not exercise its right to vote if any of its member States exercises its right, and vice versa.

Article 45: Entry into force

1. The present Convention shall enter into force on the thirtieth day after the deposit of the twentieth instrument of ratification or accession.

2. For each State or regional integration organization ratifying, formally confirming or acceding to the Convention after the deposit of the twentieth such instrument, the Convention shall enter into force on the thirtieth day after the deposit of its own such instrument.

Article 46: Reservations

1. Reservations incompatible with the object and purpose of the present Convention shall not be permitted.

2. Reservations may be withdrawn at any time.

Article 47: Amendments

1. Any State Party may propose an amendment to the present Convention and submit it to the Secretary-General of the United Nations. The Secretary-General shall communicate any proposed amendments to States Parties, with a request to be notified whether they favour a conference of States Parties for the purpose of considering and deciding upon the proposals. In the event that, within four months from the date of such communication, at least one third of the States Parties favour such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of two thirds of the States Parties present and voting shall be submitted by the Secretary-General to the General Assembly for approval and thereafter to all States Parties for acceptance.

2. An amendment adopted and approved in accordance with paragraph 1 of this article shall enter into force on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment. Thereafter, the amendment shall enter into force for any State Party on the thirtieth day following the deposit of its own instrument of acceptance. An amendment shall be binding only on those States Parties which have accepted it.

3. If so decided by the Conference of States Parties by consensus, an amendment adopted and approved in accordance with paragraph 1 of this article which relates exclusively to articles 34, 38,

39 and 40 shall enter into force for all States Parties on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment.

Article 48: Denunciation

A State Party may denounce the present Convention by written notification to the Secretary-General of the United Nations. The denunciation shall become effective one year after the date of receipt of the notification by the Secretary-General.

Article 49: Accessible format

The text of the present Convention shall be made available in accessible formats.

Article 50: Authentic texts

The Arabic, Chinese, English, French, Russian and Spanish texts of the present Convention shall be equally authentic.

In witness thereof the undersigned plenipotentiaries, being duly authorized thereto by their respective Governments, have signed the present Convention.

REPORT AND DATA ON POPULATION AND PERSONS WITH DISABILITIES IN THE REPUBLIC OF SAN MARINO¹⁰⁸

The number of residents in the Republic of San Marino is of 32.404 to the 31st of July 2012. The number of inhabitants, including persons with a residency permit, rises up to **33.506**

Population structure by age group	- From 0 to 15: 16.7% (M: 2,482; F:2,328)
	- From 16 to 64: 66.5% (M: 9.255; F: 9,943)
	- Over 65: 16.9% (M: 2,106; F: 2,766)
Average Age	- Male: 39.91
	- Female: 40.65
	- Whole population: 40.29
Growth rate population	1.3%
Birth rate	10.18 births/1000 inhabitants
Death rate	8.07 deaths/1000 inhabitants
Fertility rate	1.33 children per woman
Infant death rate	4.73 /1000 (the lowest rate in the world)
Life expectancy	81.4
Population structure by gender	- At birth: 1.09male/1 female
	- Under 15: 1.07 male/1 female
	- From 15 to 64: 0.93 male/1 female
	- Over 64: 0.76 male/1 female
	- Whole population: 0.92 male/1 female
Religion	- Catholic 88.7%
	- Pentecostal 1.8%
	- Other 9.5%
Language	Italian and dialect

¹⁰⁸ Data updated on the 31st January 2013 and provided by the Informatics, Technology Data and Statistics of the Economic Programming Office and by the Simple Departmental Organizational Unit Disability and Residential Assistance of the National Social Security Institute of the Republic of San Marino.

The percentage of persons with disabilities, out of the whole population, refers to the seriousness of the disability and to the access persons with disabilities have to some of the provided services.

Listed below is some data regarding persons with disabilities who benefit from some of the services provided by the National Social Security Institute (ISS) of San Marino as well as an indicative number of persons with disabilities who attend school at different stages.

Signed up in the unemployment register	Data not available
Employment in industry, handy craft and services sectors	25
Persons with disabilities who receive rehabilitative treatment	90
Persons with disabilities who attend the two rehabilitation centres in the territory	45
Users that receive at least one treatment a year (including persons with motor, speech disabilities, etc.)	300
Guests with disabilities resident in the Centre for Persons with Disabilities "Colore del Grano"	13
Persons with disability who belong to the UOSD Disability of the Social Security for the services it provides	85

Persons with disabilities who attend schools, divided by schools during the year 2012/2013 and recognized by the Technical Commission for Integration, excluding some Specific Learning Disorders or similar conditions.

Nursery school	3
Kindergarten and primary school	25
Middle and high school	27
	(including the Centre for Professional Training and including the students enrolled in high schools outside the territory of San Marino).

The associations in the Republic of San Marino that work and promote actions with and for persons with disabilities are:

- the **San Marino Special Sport Federation**. The federation is member of the National Olympic San Marino Committee (CONS) and other sports associations (www.fsss.sm);
- **Attiva-mente** is a sports and cultural association for persons with disability in San Marino, that includes the Paralympic Committee of San Marino (www.attiva-mente.org);
- There are 12 association that deal with disability within the council of the Associations and Cultural Cooperatives of San Marino (www.associazioni.sm).

The Republic of San Marino ratified:

- 4 February 2008 *The UN Convention on the Rights of Persons with Disability and its Optional Protocol*
- 26 February 1998 *the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine*

Legislations in San Marino protecting the rights of persons with disabilities:

- Law no. 141 of 21 November 1990 "Framework Law for the protection of the rights and inclusion of persons with handicap"
- Law no. 71 of 29 May 1991 "Access to employment for invalid and disabled people"
- Law no. 137 of 29 October 2003 "Family supporting measures"
- Law no. 92 of 30 July 2007 "Extension of benefits envisaged in art. 5 of Law n. 137 of 29 October 2003"
- Law no. 134 of 30 November 1995 "Rules on issuance of driving licence"
- Law no. 160 of 21 September 2010 "Rules on Social and Service Cooperation"

Legislations in San Marino on education:

- Law no. 60 of 30 July 1980 "Reform of the school system"
- Law no. 37 of 4 March 1993 "Rules on vocational training and employment promotion policies"
- Law no. 21 of 12 February 1998 "General rules on education"
- Law no. 68 of 25 May 2004 "Rules on socio-educational services for early childhood".



DPI EUROPE POSITION STATEMENT ON BIOETHICS AND HUMAN RIGHTS

DISABLED PEOPLE SPEAK ON THE NEW GENETICS **DPI EUROPE POSITION STATEMENT ON BIOETHICS AND HUMAN RIGHTS** **A project funded by the European Commission**

About DPI

Disabled Peoples International (DPI) is a human rights organisation committed to the protection of disabled people's rights and the promotion of their full and equal participation in society. Established in 1981, DPI is represented through active membership of national organisations of disabled people in over 130 countries, including 29 in the European region (DPI Europe).

Background to the project

From pre-natal screening and the selective termination of 'undesirable' pregnancies to euthanasia of disabled adults, one of the biggest threats to the rights of disabled people this Millennium lies within the field of bioethics - the ethics of advances in biological medicine and science. If disabled people's rights are to be protected, it must be in a context where we are confident that society is willing to share burdens and support those whose needs are greater than others to ensure equality of opportunity.

The European disability movement has been working towards this in the context of civil rights but there has been little action in the area of bioethics. Generally, disabled people have been unaware of the fundamental issues and excluded from discussions.

In order to address these issues and to become active, knowledgeable partners, a project on bioethical issues was initiated in accordance with DPI Europe's Action Plan 1999 – 2002, adopted in Syracuse, Italy. One of its priority areas is "... to influence the European Union, Council of Europe and national governments in their way of thinking on bioethical concerns..." and "... to educate disabled people within Europe and the rest of the world on .. bioethics".

A working group represented by members of DPI Europe in France, Italy, Portugal, Spain and the UK was set up early in 2000 to discuss the issues from a disability perspective and develop the position statement you will find here.

We have consulted with all our European members and they will now embark on a process of disseminating and discussing the information at national level.

LETTER FROM THE CHAIR

The world is changing rapidly. We are witnessing technological revolutions, economic and social transformations, profound modifications in ethics and values. Whilst the ordinary citizen is not consulted or questioned, the consequences of these changes may often profoundly affect the quality of our lives.

The field of biomedicine is one of these areas where profound changes are taking place and which will dramatically affect the lives of disabled people. Disabled people fear that their human rights are once again being threatened and are particularly concerned about the potential for new forms of discrimination inherent in scientific and technical 'progress'. Already discriminated against widely and habitually, disabled people in the European Union, represented by Disabled Peoples' International, wish to express their concerns and recommendations loudly and forcefully to society as a whole. To that end, DPI Europe organised the first international conference on Bioethics and Disabled People's Human Rights in Solihull (UK) and embarked on a consultation exercise within its membership to develop a European statement which reflects the concerns and demands of disabled people. This statement, which we hope will form the basis of discussion for an international document to be presented to the United Nations, is the result of a European project funded by the European Commission.

This project has been made possible thanks to the direct participation and input of disabled people from 5 member states; the competence of Bill Albert, Chair of the European Working Group; the commitment of Rachel Hurst, DPI Special Rapporteur, Human Rights; and the coordination work of Julie Marchbank, Project Manager. A special thanks is expressed to Arthur Verney, Development Worker of DPI Europe, who has devoted his energies to carrying out DPI Europe's actions during the past 8 years.

As of today, there will be no debate on bioethics without the voice of disabled people being heard.

Giampiero Griffo, Chair, DPI Europe

DISABLED PEOPLE SPEAK ON THE NEW GENETICS

INTRODUCTION

“All Human Beings are born free and equal in Dignity and Rights”

Universal Declaration of Human Rights, 1948

Nuclear energy is a source of life and a cause of death. If given an opportunity to express their opinion surely the victims of Nagasaki or Chernobyl would have fought for stricter regulation of the practical use of that new scientific knowledge. The same is true of the revolutionary developments in human genetics.

Many disabled people are only alive today because of scientific progress generally and new medical techniques in particular, so of course we wish to promote and sustain such advances where these lead to benefits for everyone. But we want to see research directed at improving the quality of our lives not denying us the opportunity to live.

The genetic goal of the prevention of disease and impairment by the prevention of lives judged not to be “normal” is a threat to human diversity. It is a potential Nagasaki for everyone, not just disabled people. The threat is powerful and imminent.

Human genetics poses a threat to us because while cures and palliatives are promised, what is actually being offered are genetic tests for characteristics perceived as undesirable. This is not about treating illness or impairment but about eliminating or manipulating foetuses which may not be acceptable for a variety of reasons. These technologies are, therefore, opening the door to a new eugenics which directly threatens our human rights.

- We are threatened when M. Rietdijk, a Dutch physician and philosopher, writes: “A baby should be killed whenever some physical or mental defect is discovered before or after birth.”
- We are threatened when Peter Singer, a professor of bioethics, writes: “It does not seem quite wise to increase any further draining of limited resources by increasing the number of children with impairments.”
- We are threatened when Bob Edwards, a world-famous embryologist, says: “Soon it will be a sin for parents to have a child which carries the heavy burden of genetic disease.”
- We are threatened by selection which leads to the discarding of potentially impaired embryos.
- We are threatened by abortion laws which discriminate against the birth of disabled children.
- We are threatened by the promise of genetic manipulation to eliminate all those differences that non-disabled people consider unacceptable.

This has all happened before. It must not be allowed to happen again.

We want to live as active, equal and productive members of society, but our perceived value and role as well as our human rights are continually diminished by the questionable medical ideas and discriminatory attitudes spawned by the new genetics.

How can we live as equal citizens in society which uses negative images of us to justify the raising of funds for charity and research. This amounts to using disabled people as evidence of the need for our own elimination. We are continually being disabled by such images. How can we live with dignity in societies that spend millions on genetic research to eradicate disease and impairment, but refuse to meet our needs to live dignified and independent lives?

We cannot. We will not.

The genetic threat to us is a threat to everyone. The value of life must not be reduced to a matter of genetic inheritance. If that is allowed to happen no potential child will be safe from arbitrary selection, no parents will escape the moral burden of making impossible choices and no one will be safe from genetic discrimination.

“Everyone has a right to respect for their dignity...that dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity”

Universal Declaration on the Human Genome and Human Rights, 1997

Our experience as disabled people places us in a unique position to contribute to a comprehensive ethical discourse leading to scientific development which respects and affirms the essential diversity of humankind.

Maintaining diversity is as essential for humanity as it is for life as a whole. Our lives as disabled people celebrate the positive power of diversity. Our experience enriches society. These are our unique gifts to the world.

FOR OURSELVES, FOR EVERYONE, WE WILL NOT GO QUIETLY INTO THE GENETIC NIGHT

POSITION STATEMENT & DEMANDS

DPI Europe is greatly concerned about the threat posed to our human rights by developments in human genetics research and practice and by the fact that our voice struggles to be heard in the ethical and scientific debates. In general we have been considered as little more than the passive subjects both of these debates and of genetic research. This has been a profoundly disabling experience.

We are also concerned that the new genetics is fostering a biologically reductive vision of the world which not only undermines what it is to be human but also devalues the importance of social factors, relationships, mutual respect and the environment in determining everyone's quality of life.

“My guess is that cells will be programmed with synthetic messages within 25 years....The point that deserves special emphasis is that man may be able to program his own cells long before he will be able to assess adequately the long-term consequences of such alterations, long before he will be able to formulate goals, and long before he can resolve the ethical and moral problems which will be raised.”

Marshall Nirenberg, Nobel Laureate, 1967

Disability, according to the World Health Organisation, is the interaction between people with impairments and environmental barriers, including those of patronising attitudes and images. The new human genetics and cultural and political ideologies which underpin it are working directly against this definition and instead fosters the concept of disabled people as being no more than their impairments. This medicalisation of disability leads to increased discrimination against disabled people and lends support to the massive financial commitment to human genetic research at the expense of tackling the disabling physical and social environment. It is the negative results of the interaction with this environment which disables us, not our impairments, whether they be genetic in origin or, as is the case with the vast majority of disabled people, caused by illness, accident or armed conflict.

We stress that disabled people do not oppose medical research where the object is genuine treatment or the alleviation of pain. What we do oppose is genetic cleansing, driven by profit motive and social efficiency, informed by prejudice against disabled people and carried out in the name of cure or treatment.

Disabled people have faced enforced sterilisation, pre-natal termination, infanticide, euthanasia and wholesale elimination. We were left out on the hills of Sparta to die, sterilised by “caring” doctors in the US, Scandinavia and Germany and were the first to be driven into the Nazi gas-chambers. We testify to the historic and continued links between genetics and eugenics. These links pose dangers for everyone, not just disabled people.

With respect to the impact of genetics on reproduction, we support women's right to choose with respect to their pregnancies. However, we deplore the context in which these choices are made.

- There can be no informed choice as long as genetic counselling is directive and misinforms parents about the experience of disability.
- There can be no free choice as long as the myths, fears, stereotypes of and discrimination against disabled people continues.
- There can be no free choice if women are under social pressure to accept routine tests.
- There can be no real choice until women feel able to continue with a pregnancy knowing that they will be bringing their child into a welcoming society that provides comprehensive systems of support.

We are concerned that the law in most countries discriminates against disabled people by allowing termination of pregnancies after a specified time, if the prospective child might be disabled, yet such discrimination is widely outlawed on the grounds of race and gender. This medicalisation of the quality of life diminishes the value of disabled people's lives and those of everyone.

We are deeply alarmed that without proper social and medical support, disabled people are often made to feel a social burden and are under pressure to choose the option of legalised euthanasia.

We repudiate the utilitarian ideology which informs much of the new human genetics, particularly the assumption that society would be better off without the inconvenience and expense of disabled people. In contrast, we want to see all clinical practice based on strong principles of justice, ethics and non-discrimination with a respect for diversity, autonomy and fully informed choice.

“... all people have the right to have been conceived, gestated and born without genetic manipulation...”

Council of Responsible Genetics – Genetic Bill Of Rights - 2000

DEMANDS

Recognising that advances in human genetics and medical-based quality of life decisions raise serious ethical issues for both disabled and non-disabled people, issues which must be considered within the framework of the essential enduring diversity of humankind;

We demand that:

1. the use of new human genetic discoveries, techniques and practices are strictly regulated to avoid discrimination and protect fully, and in all circumstances, the human rights of disabled people,
2. genetic counselling is non-directive, rights based, widely and freely available and reflects the real experience of disability,
3. parents are not formally or informally pressured to take pre-natal tests or undergo “medical” terminations,
4. all children are welcomed into the world and provided with appropriate levels of social, practical and financial support,
5. human diversity is celebrated and not eliminated by discriminatory assessments of quality of life which may lead to euthanasia, infanticide and death as a result of non-intervention,
6. organisations of disabled people are represented on all advisory and regulatory bodies dealing with human genetics,
7. legislation is amended to bring an end to discrimination on the grounds of impairment as exceptional legal grounds for abortion,
8. there is a comprehensive program of training for all health and social care professionals from a disability equality perspective,
9. as the human genome is the common property of humanity, no patents are allowed on genetic material,
10. the human rights of disabled people who are unable to consent are not violated through medical interventions.

BASIC GENETIC PROCEDURES AND CONCEPTS

“The end product of genetic and related research should not be the elimination of disability, but improved information on disability, improved treatment of potentially disabling conditions, and improved support for people with disabilities.”

Inclusion Europe, Reference Document on Bioethics, 1999

PRE-NATAL SCREENING AND TESTING

Pre-natal screening is carried out on large numbers of pregnant mothers to check on abnormalities in the foetus. This will be done by routine procedures such as ultrasound scanning or a simple blood test.

Pre-natal testing – using the same techniques, is done when the family has a genetic marker or predisposition for a certain condition and the pregnant woman wishes to take the test.

As a result of screening, when the foetus is seen to be ‘at risk’, testing will then be carried out by use of amniocentesis - the insertion of a needle into the uterine cavity to withdraw fluid for testing for certain conditions, most commonly Downs Syndrome and neural tube defects.

Issues

- Amniocentesis carries a risk of miscarriage – about 1-2%.
- Tests are not always accurate either on verifying whether the condition actually exists or on the degree of severity.
- The underlying reasoning for pre-natal screening and testing is the elimination of impaired foetus. This sends a discriminatory message to say that disabled people’s lives are not worth living or worthy of support.
- Counselling before and after testing is often cursory, with expectations that the woman will abort if the test is positive. Counselling should be free, comprehensive and non-discriminatory and should involve disabled people with similar conditions as well as parents.
- Choices of which condition and what level of severity should lead to abortion are made on the basis of myths, fears and stereotypes, not the reality of disabled people’s experience

“The NDCS does not support the genetic screening of whole populations for genetic conditions, with the consequent risk of moving towards a society in which difference is no longer accepted or tolerated”

National Deaf Children’s Society (UK) NDCS Policy Statement on Genetics and Deafness, 1999

PRE-IMPLANTATION GENETIC DIAGNOSIS

This is a technique where couples can have their embryos tested for certain impairments before being implanted in the uterus. This allows couples to eliminate the impaired foetus and ensure implantation of a non-impaired foetus. This is now being used for those who are at particular risk of passing on an inherited condition such as Tay Sachs, Duchenne Muscular Dystrophy, Cystic Fibrosis etc. At the moment it is only used through IVF (in vitro fertilisation).

Issues of concern

- Couples who might otherwise not have had a baby, are able to choose a baby which is 'guaranteed' not to have the particular impairment.
- IVF has its own risks and fertility does not always result.
- As further genetic markers are discovered, couples will have more complex choices, which could include physical and personality characteristics as well as impairments.
- As with screening, pre-implantation diagnosis assumes that disabled people are less valuable and that impairment should be avoided. A stereotypical image of the perfect baby is promoted. These assumptions discriminate against disabled people and encourage negative attitudes to our quality of life.
- Again, other people are making assumptions on our quality of life.

"..people with spina bifida and hydrocephalus live a full life with equal value to that of any other citizen and should not be seen as a medical condition"
International Federation for Hydrocephalus and Spina Bifida, Toulouse statement 2000

INFANTICIDE ON THE GROUNDS OF IMPAIRMENT

This is the killing of a baby who is thought to be so severely disabled that it is not allowed to survive. Death can be caused by use of sedation and cessation of feeding or happen because no attempts are made to clear the airways. Sometimes the justification given is that the baby is not yet a person with attendant rights and that anyway life would be miserable.

In some countries (notably the UK) a mother who is found guilty of infanticide while she is still breast-feeding or shortly after the birth will be found guilty of manslaughter. For anyone else, the killing would be regarded as murder.

Issues of concern

- Sometimes it is felt that as the tests do not necessarily reveal the extent of impairment, it is better to wait until after the child is born before deciding if the child should live. This is, of course, contrary to law and rights which both acknowledge that life starts with the first breath.
- Disabled people's quality of life is measured against medical prediction (not provable facts), economic standards and cultural attitudes. Little recognition is given to the duty of society to support the parents and the disabled child so that the costs and impacts of impairment are

diminished and to ensure that the disabled child is welcomed into the human family with the same degree of pleasure as a non-disabled child.

EUTHANASIA

This is the concept of an 'easy death' – the act of killing someone painlessly, especially to relieve suffering from an incurable and painful illness. There are three types of euthanasia:

- Voluntary euthanasia is at the request of the person who wishes to die,
- Non-voluntary euthanasia is when a person is unable to request it due to physical and/or mental incapacity and the medical profession and the courts of law deem it necessary. An example of this would be the decision to stop feeding and hydrating (giving fluids) to someone who is in a Persistent Vegetative State (PVS)
- Involuntary euthanasia is when someone could have consented or refused but were not asked. For example, the application of Do Not Resuscitate (DNR) notices to elderly or disabled patients' hospital records without their knowledge.

"..no-one shall be subjected without his free consent to medical or scientific experimentation."

International Covenant on Civil and Political Rights, 1966

Issues of Concern

- Supporters of euthanasia argue that voluntary euthanasia is a matter of personal choice without recognising the sometimes very persuasive powers of doctors and relatives who may have subjective reasons for hastening the death of an individual, and the lack of palliative care and support services available to ensure a better quality of life.
- People who are not able to verbally communicate are particularly vulnerable to abuse of euthanasia – administered in 'their best interests' but without their informed consent. Research in the Netherlands, the only country to have decriminalised voluntary euthanasia, has shown a significant rise in the death rates of people with intellectual impairments within institutional settings.

"Limiting the focus to the gene obstructs perception of the multiple facets of the phenomenon of illness"

Nuremberg Code, IPPNW, 1997

GENETIC DETERMINISM

Genetic determinism is the view that we are the sum of our genes, that they predict the impairments and behaviour we will exhibit throughout our lives and that the environment has no real influence.

Issues

- A genetic marker of a particular condition is not the whole story about that gene. A gene is a store of information that determines the sequence of a protein. A specific characteristic arises from the interaction of proteins, cells and tissues and is not just the gene itself. Science still does not know how the whole process works.
- Knowing that you have a marker for a certain condition can ensure that you adopt a lifestyle that will prevent that condition developing.
- The environment has a part to play in what happens to us and is the cause of the majority of disabling impairments – through poverty, accidents, war, environmental hazards etc.
- Genetic determinism has given rise to the opposite theory that so many genes are involved in the development of characteristics that it will be impossible to actually predetermine someone's impairments. This is also a flawed concept, in that research has shown clearly that although there is interaction between genes and how they work, the numbers of genes involved are often small and well within the capacity of modern computer testing.
- Believing that genes are all we are gives emphasis to the idea that impairment and disabled people should be eliminated and removed from the gene pool, ignoring the fact that it may be that nearly everyone will have a genetic flaw of some sort or another. This will give rise to even further delineation between acceptable and unacceptable characteristics.
- The use of genetic information has already led to genetic discrimination in employment and insurance and this problem is likely to increase substantially.

“No-one shall be subjected to discrimination based on genetic characteristics that ..has the effect of infringing on human rights, fundamental freedoms and human dignity”

Universal Declaration on the Human Genome and Human Rights, 1997

GENE THERAPY

Gene therapy involves making changes to the gene in order to treat a condition. This could be done by adding a working copy of the faulty gene, by developing genetic-based drug therapy or, as has already been unsuccessfully tried, by imparting a virus into the faulty gene.

There are two kinds of gene therapy:

Somatic gene therapy - alters the individual gene level.

Germ line therapy (or human genetic engineering) – alters all the cells in the body, including the reproductive cells and therefore can be passed on through reproduction. This therapy is prohibited in most countries at the moment.

“An intervention seeking to modify the human genome may only be undertaken for preventative, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants”

European Convention on Human Rights and Biomedicine, 1997

Issues

- Although somatic gene therapy and gene-based drugs could be seen as just another form of medicine, there are important ethical concerns around research, consent and experimental treatments, which are arising from the behaviour of scientists and pharmaceutical companies in their bid to win the race and make huge profits.
- Human Genetic engineering raises major questions both about the nature of life itself and the danger of passing on unknown gene combinations to future generations.
- Gene therapies are being publicised as the solution for impairments and research funds are being raised through the portrayal of disabled people as helpless victims of disease. This emphasis on the medical model of disability is further weakening the arguments for funding proper social support for disabled people to live fully and equally in their communities.

“..genetic invasion into human embryonic development...has serious and incalculable effects for future generations. As such, it is not justifiable”

Nuremberg Code, IPPNW 1997

GENE PATENTING

This enables commercial enterprises to obtain patents on genetic material when discovered and removed from the body or on manipulations of genetic material. They can then charge anyone wishing to use that discovery in the process of medical research or drug development. The commercial companies say that this patenting is essential to cover the costs of research. The power of the commercial interests supports the introduction of genetic engineering on plants and animals without adequate research on its consequences on the environment. Although intended to protect scientific invention, the EU has recently issued a Directive on the Legal Protection of Bio-technological Inventions which permits the patenting of discoveries of human genes and gene sequences. This has already had serious cost implications for some national health services, for example in the UK.

Issues

- Patenting maximises profits rather than making treatments available
- Physicians have an ethical obligation not to permit profit motives to influence their free and independent medical judgement. For physicians to pursue, obtain or enforce medical process patents could violate this requirement.
- Treatments will become much more expensive.

- Commercial companies will race to obtain the greatest number of patents regardless of research potential.
- Disabled people in search of cures have been used by pharmaceutical companies to support patenting in Europe.

“The human genome in its natural state shall not give rise to financial gains”

Universal Declaration on the Human Genome and Human Rights, 1997

HUMAN GENOME PROJECT

This project has now sequenced the complete set of chromosomes that humans pass on to their offspring – commonly known as the Book of Life.

The genetic code is now known but what each bit does and how it works is still a mystery. Towards the end of the project it was agreed to put the results on the internet, thus stopping commercial concerns rushing out to patent individual genes.

Issues

- The sequencing of the human genome will change the way we understand ourselves and reinforce the view that we are little more than our genes. Yet they are only part of the puzzle. We have yet to learn about how development and environment influence the way we are.
- Eventually, using the information of the genome, we could eradicate many diseases, ensure longevity and replicate organs as well as design human beings. Being able to make such choices increases the problem of discrimination on the grounds of genetic information and the potential of creating an underclass of genetically imperfect humans.
- Confidentiality of personal genome information will be a serious problem, especially in the areas of health care and insurance

“...we live in an age where although we think of ourselves as scientists and democrats..there is a large residue of pre-science and pre-democracy conceptions and values...a large residue of what our ancestors called barbarism. ...If science of genetics is controlled by barbarians, it will be used to perpetuate barbarism....There doesn't seem to be any divine mandate that we as human beings are going to automatically progress to the promised land. “

Justin Dart, Disabled Activist, 1997



DECLARATION OF SOLIHULL, 2000

DISABLED PEOPLES' INTERNATIONAL EUROPE
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THE RIGHT TO LIVE AND BE DIFFERENT

On 12/13 February 2000, 130 disabled people and parents, delegates from DPI organisations in twenty-seven countries in Europe, African, Australia and North America, met in Solihull, UK to discuss bioethics and human rights. This was the first occasion of its kind and it is with pride that we make the following declaration.

First and foremost we demand:

Nothing about us without us

Up until now most of us have been excluded from debates on bioethical issues. These debates have had prejudiced and negative views of our quality of life. They have denied our right to equality and have therefore denied our human rights.

We demand that we are included in all debates and policy-making regarding bioethical issues.

We must be the people who decide on our quality of life, based on our experiences.

We also call on our organisations to give support, encouragement and reassurance to those of us who are representing our views on bioethical regulatory bodies.

Particular support must be given to empower the voice of mental health survivors, people with learning difficulties, people who cannot advocate for themselves and disabled children, in the debate.

RICHNESS IN DIVERSITY

We are full human beings. We believe that a society without disabled people would be a lesser society. Our unique individual and collective experiences are an important contribution to a rich, human society.

We demand an end to the bio-medical elimination of diversity, to gene selection based on market forces and to the setting of norms and standards by non-disabled people.

Biotechnological change must not be an excuse for control or manipulation of the human condition or bio-diversity.

We recognise that the only way to ensure universal support for and positive recognition of our particular qualities is through stating our right to diversity clearly, with good arguments, in open

and democratic discussion. We must form alliances with scientists, the medical professions, ethicists, policy-makers, human rights advocates, the media and the general public.

All Human Beings are born free and equal in Dignity and Rights

Human rights are the responsibility of the state as well as the individual. Disabled people, our organisations, families and allies must work to ensure that international, regional and national legal instruments include the implementation of rights throughout all scientific advances and medical practices concerning the human genome, reproduction, assessments of quality of life, therapeutic measures and alleviation of 'pain and suffering'.

Biotechnology presents particular risks for disabled people. The fundamental rights of disabled people, particularly the right to life, must be protected.

In particular we demand:

- An absolute prohibition on compulsory genetic testing and the pressurising of women to eliminate - at any stage in the reproductive process – unborn children who, it is considered, may become disabled
- The provision of full and accessible (ie. jargon-free, easy to read and in alternate media) information from which people can make informed decisions
- That European governments do not ratify the Convention on Human Rights and Biomedicine as some sections are in contravention of the two documents adopted at the 1999 UNESCO Conference on Sciences
- That disabled people have assistance to live - not assistance to die
- That having a disabled child is not a special legal consideration for abortion
- That no demarcation lines are drawn regarding severity or types of impairment. This creates hierarchies and leads to increased discrimination of disabled people generally.

**Disabled people must join together in solidarity to ensure our voices in
these life-threatening issues.**

STRENGTH IN UNITY!

RESOLUTION ON ACTIVE TERMINATION OF LIFE OF NEWBORN CHILDREN WITH SPINA BIFIDA
AND/OR HYDROCEPHALUS AND THE RIGHT TO LIVE



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA AND HYDROCEPHALUS

Consultative status special category with Economic and Social Council of the United Nations
Participatory status, Council of Europe

**RESOLUTION ON ACTIVE TERMINATION OF LIFE OF NEWBORN CHILDREN
WITH SPINA BIFIDA AND/OR HYDROCEPHALUS AND THE RIGHT TO LIVE**

**Adopted by the IF Annual General Meeting
on 30 June 2006 in Helsinki**

1. Introduction

In its 2000 resolution *Prenatal Diagnosis and The Right to be Different* IF already sharply condemned active termination of life on the grounds of disability. This selection and termination of life on the grounds of disability is now extended to newborn children with impairments as shown by the Dutch 'Groningen Protocol' (published in *New England Journal of Medicine* 2005; 352:959-962). The Groningen Protocol advocates legislation on the active termination of life of newborn children with severe impairments. The proposed legislation is to widen the euthanasia legislation to newborns.

The paediatricians from Groningen that developed the Protocol documented 22 cases, all concerning children with neural tube defects whose lives were actively ended with the approval of the Public Prosecutor. They argue that these newborn children were 'in agony' or 'suffering unbearably and hopelessly'. These arguments for having ended the lives of the 22 babies are now being contested by other paediatricians in the Netherlands who claim that spina bifida is no reason for unbearable suffering and that in those cases where a newborn child is suffering many means to alleviate the pain are available.

Proposing parents to actively end the life of their newborn child with Spina Bifida and/or Hydrocephalus puts considerable psychological pressure on them. Arguments of the negative quality of life of people with Spina Bifida and/or Hydrocephalus are put forward and their extra social and medical costs are emphasised, which violate the internationally accepted human rights principles. Instead, parents of a newborn child with Spina Bifida and/or Hydrocephalus should be provided with concrete experiences on disability.

This IF resolution underlines the right to live of all newborn children with Spina Bifida and/or Hydrocephalus and the right to access all treatments which can improve their quality of life and prevent them from further impairment.

2. Combining the medical and the social approach

The conditions for a good quality of life depend on many factors which are equal for all children irrespective of their physical and intellectual condition. One's future quality of life cannot be predicted. The vision that newborn children with Spina Bifida and/or Hydrocephalus will have a bad quality of life only takes the medical approach into account, which locates the phenomenon of disability exclusively within the individual. However, since its 2001 publication *International Classification of Functioning and Disability (ICIDH-2)*, the World Health Organization considers disability an umbrella term combining the existing medical and social definitions. The latter clarifies that the impairment of a capacity does not count in itself as a disability, but becomes a disability if treated by society in a manner that disadvantages the person with impairment. The argument of a bad quality of life as implied in the Groningen Protocol contradicts this universally accepted vision. The fight of the right to life includes a needed commitment of the society on the path of the quality of life of people with Spina Bifida and/or Hydrocephalus.

3. International instruments promoting human rights

Several internationally adopted instruments promote the right to live of newborn children with impairments including the *UN Universal Declaration of Human Rights (1948)* and the *UN Convention on the Rights of the Child (1989)*. The Groningen Protocol as such breaches article 1 and 3 of the former and article 6 and 24(1) of the latter. The *Convention for the Protection of Human Rights and Fundamental Freedoms (1950)* of the Council of Europe too, unequivocally provides in its article 2 that "everyone's right to life shall be protected by law." This principle is also reflected in article II-62 of the current draft of the *Constitution for Europe*. The Constitution's articles II-61 and II-63 respectively refer to the Human Dignity and to the Right to the Integrity of the Person.

4. Proposal

The IF members at their Annual General Assembly, held the 30th of June 2006 in Helsinki, have agreed the following resolution and decided to transmit it to all relevant stakeholders at the national and international level:

1. All newborn children with Spina Bifida and/or Hydrocephalus have the right to live and to all treatments which can improve their quality of life or prevent further impairment. Active termination of life of newborn children with Spina Bifida and/or Hydrocephalus should not be permitted on the basis of their expected quality of life;
2. Spina Bifida and/or Hydrocephalus should never be an argument not to provide available life-saving and life-improving treatment;
3. Pain and suffering of the newborn child should not promote the solution of active termination of life, but rather the alleviation of that pain and suffering;

4. It should be acknowledged that differences enrich society and that all people can contribute to society as soon as these differences are accepted and means are provided in favour of inclusion. The level of a society's civilization can be measured by the attitude towards those people who find themselves on the other side of the spectrum of what is regarded as the norm;
5. Erroneous societal assumptions about the quality of life of people with Spina Bifida and/or Hydrocephalus or social provision cost factors should not justify active termination of life on the grounds of disability. These violate the internationally accepted human rights principles;
6. Organisations of Spina Bifida and Hydrocephalus must be full partners in debates on the moral and ethical dilemmas raised by decision making for newborn children with Spina Bifida and/or Hydrocephalus;
7. Counselling for parents should be supportive, focusing on all aspects of life for a child with Spina Bifida and/or Hydrocephalus. Parents should be informed about all recent scientific advances that have improved considerably the quality of life of people with Spina Bifida and/or Hydrocephalus, and about legislative initiatives, including non-discrimination and human rights legislation, which offer more legal protection to disabled people and their families. Parents should be given time to adapt to their new situation and should feel free to make fully informed decisions;
8. Any explicit or implicit bias, practice or procedure in counselling that devalues the worth of the life of people with Spina Bifida and/or Hydrocephalus is a form of discrimination and is in breach of human rights principles and may be open to legal challenge;
9. Any form of discrimination against people with Spina Bifida and/or Hydrocephalus should be outlawed including in any legislation on active termination of life of newborn children with impairments;
10. The wording euthanasia is misleading when it concerns a newborn child with Spina Bifida and/or Hydrocephalus that is not dying and should in that case not be used interchangeably with active termination of life.

European Disability Forum

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**RESOLUTION ON PRE NATAL DIAGNOSIS
AND THE RIGHT TO BE DIFFERENT**
adopted by the EDF Annual General Assembly on 24 May 2003 in Athens

1. Introduction

New methods of early diagnosis, such as ultra sound and amniocentesis, have given parents the opportunity to know some of the physical conditions of their unborn child. More recently, advances in the genetic sciences and the DNA have increased knowledge of which gene may result in a certain condition or which will give a predisposition to a condition.

These scientific advances have fed the fear of the birth of a disabled child and prejudgements of their potential quality of life. In Western countries, over 90% of parents opt for abortion or termination of pregnancy when the unborn child appears to have an impairment. Parents are demanding embryo selection, (though in some countries this is not legal except for In Vitro Fertilisation and some specific cases). Considerable pressure is put on parents who do not want to abort or terminate the life of their child. Arguments of the negative quality of the life of disabled people are put forward and the extra social and medical costs of a disabled child are emphasised. Very little counselling is available and rarely are adults with a similar condition involved.

There has been an increase in knowledge of planned parenthood and primary prevention – for instance, taking folic acid before and during the first part of pregnancy, not smoking, a balanced diet for the mother etc. All these preventative methods have shown a marked decrease in the numbers of births of babies with impairments. Nevertheless, secondary prevention (abortion etc) is still seen as the most effective method of the elimination of disease or impairment.

This EDF resolution does not intend to put into question the right to abortion principle, but rather to address the discriminatory approach in relation to disability practiced in the implementation of this right.

The way society responds to the rights and needs of disabled individuals influences dramatically their quality of life. Lacks of services, access to the community and equal opportunities for participation makes a person's life of poor quality. Most importantly, a crucial element in ensuring a good quality of life is the acknowledgement by society that the life of a disabled person is just as important and worthwhile as anyone else's.

2. Proposal

The European Disability Forum meeting at its Annual General Assembly on May 24 2003 in Athens has agreed the following resolution and decided to transmit it to all relevant stakeholders at National and European level:

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DOC-AGA-03-05-11-A



1. By this resolution, disability organisations do not intend to put into question the right to abortion principle, but rather to address the discriminatory approach in relation to disability practiced in the implementation of this right;
2. Prenatal diagnosis for genetic impairments, which is based on the value judgement that one life is worth less than another, should not lead to termination of pregnancy. Nor should erroneous societal assumptions about the quality of life of disabled people or social provision cost factors justify abortion on the grounds of disability;
3. Organisations of disabled people must be full partners in debates on the moral and ethical dilemmas raised by pre-natal diagnosis;
4. Prenatal counselling for parents should be carried out by skilled professionals in a multi-disciplinary team that should include adults with a genetic condition. Counselling should be supportive and should focus on all aspects of life for a child with genetic impairments and should not be linked to termination or abortion. Parents should be given time to adapt and to feel free to make fully informed decisions;
5. Relevant factors that should be addressed in counselling and decision-making should recognise that recent scientific advances have improved considerably the quality of life of disabled people and that legislative initiatives, including non-discrimination and human rights legislation, offer more legal protection to disabled people and their families;
6. Any explicit or implicit bias, practice or procedure in pre-natal counselling that devalues the worth of the life of people with impairments is a form of discrimination and is in breach of human rights principles and may be open to legal challenge;
7. After diagnosis, professionals should work with organisations of disabled people and parent's organisations to ensure that information is up-to-date, correct and understandable;
8. Prevention of genetic impairment should be through primary methods, such as a balanced diet for the mother, or refraining from smoking or drinking. Campaigns to promote these methods must safeguard the dignity of disabled people;
9. Misleading terminology such as secondary prevention or therapeutic abortion should not be used. Termination of pregnancy has no therapeutic effect on the child;
10. Further research is needed on the real cause of genetic impairments;



11. Disabled people are able to live full and fulfilling lives of equal value to that of any other citizen. They should not be seen as a medical condition but as full human beings with equal rights to life, dignity and freedom. Their views should be sought and heard by governments, policy makers and health professionals, who should acknowledge the right of disabled people to speak for themselves;
12. Disabled people have the right to lives as rewarding as those of their non-disabled peers and supportive systems should be freely available to ensure full and equal inclusion and participation;
13. Any form of discrimination against disabled people should be outlawed including in any legislation on abortion.

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Websites mentioned in this document have been visited February 25, 2013

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