

“The UN Convention on the rights
of the people with disability:
general principles and strategies
for its effective implementation”

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Outline

- Introduction: Contemporary discussion on the rights and the inclusion of people with disabilities
- International Convention: principles and challenges
- Incidence of the Convention in the Spanish Legislation

Contemporary discussion on the rights and the inclusion of people with disabilities

- Fight against discrimination
- Historical models of the treatment of disability
- International Convention

Fight against discrimination

- Feature that characterizes the contemporary history of the rights.
- It is located in the processes of generalization and of specification.
- It handles the equality as negative and positive differentiation
- It gives capacity to the rights of the persons with disability

Historical models of the treatment of disability

- Obliviousness Model
- Rehabilitation or medical Model
- Social Model
 - (Situation approach)
- Diversity Model
 - (Group approach)
- Convention
 - Social Model
 - Diversity Model

History of the Convention

- Long process in which different actors are involved
- It starts to grow in 2001
- Approval on December 13, 2006

Convention contents (preamble and 50 articles)

- General regulations (arts. 1 - 9)
- Rights (arts. 10 - 30)
- Data compilation and international cooperation (arts. 31 and 32)
- Application and supervision of the Convention (arts. 33 - 40)
- Final regulations (arts. 41 - 50)

General regulations (arts. 1 - 9)

- Art. 1. Intention of the Convention and definition of "person with disability".
- Art. 2. Meaning of communication, language, discrimination for reasons of disability, reasonable adjustments and universal design
- Art. 3 General principles that must face the interpretation and application of the Convention, from which the principles of dignity, equality and universal accessibility are emphasized
- Art. 4. General obligations assumed by the States that are obligations of respect, of protection and of fulfillment
- Art. 5. Equality and not discrimination
- Art. 6. Women and disability
- Art. 7. Children and disability
- Art. 8. Measurements to sensitize and to educate the population with regard to the rights of the persons with disability
- Art. 9. Universal accessibility

Rights (arts. 10 - 30)

- **Rights of equality:** Right to the equality and not discrimination, right to the legal capacity in all the aspects of the life; right to enjoy an accessible environment, and right to an egalitarian access to the justice.
- **Rights of protection:** Right to life protection; right the protection in risk situations; right of protection from the torture and other cruel, inhuman or degrading dealings or sorrow; right of protection from the development, the violence and the abuse; right to the protection of the personal integrity (physical and mental); right to the protection of the privacy, and right to the protection of the hearth and the family.
- **Rights of freedom and personal autonomy:** Right to the freedom and safety of the person; right to the freedom of movement, to the freedom to choose residence and nationality; right to live independently and to be included in the community; and right to the personal mobility with the biggest possible independence.
- **Rights of participation:** Right to the freedom of expression and of opinion and access to information; right to take part in the political and public life; right to take part in the cultural life and recreational activities, spare and sport.
- **Social rights:** Right to an inclusive education at every level as well as to the education along the life; right to enjoy the highest possible health level; right to habilitation and rehabilitation to achieve and to maintain the maximum independence, physical, mental, social and vocational capacity; right to have the opportunity to make the living by means of a work freely elected or accepted on an open, inclusive and accessible labor market and environment; and right to have a suitable standard of living and to the social protection.

Application and supervision of the Convention (arts. 33 - 40)

- Art. 33. National monitoring, emphasizing the possibility of the establishment of a coordination mechanism.
- Art. 34. International monitoring, creating a Committee about the Rights of the persons with disability.

Parts of the Convention that should be emphasized

- Concept of disability
- Principles that guide it
- Universal accessibility
- legal capacity
- Independent life
- Sign language speaking

Concept of disability

- “disability is a concept that evolves and that results from the interaction between the persons with disabilities and the barriers due to the attitude and to the environment that avoid its full and effective participation in the society, on equal terms with the others”
- “people with disability include those that have long-term physical, mental, intellectual or sensory disabilities that, by interacting with diverse barriers, could prevent its full and effective participation in the society, on equal terms with the others”
- Social model
- Open definition

Principles that guide the Convention

- Dignity and autonomy
- Equality and not discrimination
- Universal accessibility
- Equal legal capacity
- Independent life
- Respect to the cultural identity of the Deaf Community

The Convention: non discrimination

- Non-discrimination concept:
 - it is based on the discriminatory result and not on the will of the person
 - it includes all kinds of discrimination (direct, indirect, structural)
 - it includes the discrimination not only to the person with disability, but any “for disability reason”
 - it admits that the refusal of reasonable adjustments is a type of discrimination.
- For “discrimination because of disability” it is understandable any distinction, exclusion or restriction because of disability that has the intention or the effect of obstructing or of leaving without effect the recognition, use or exercise, in conditions of equality, of all the human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other type of field.

Convention: accesibility and adjustments

- The Convention establishes that the States Part will have to adopt measurements adapted to assure the access of the persons with disability, on equal terms with the others, to the physical environment, the transport, the information and the communications; they will include the systems and the information technologies and the communications, and to other services and facilities opened to the public or of public use, both in urban and rural areas. These measures will include the identification and elimination of obstacles and barriers of access in any field.
- The reasonable adjustments are “the modifications and necessary and suitable adaptations, that do not suppose a disproportionate or inadequate load, when they are needed in a particular case, to guarantee to the persons with disability the use or exercise, on equal terms with the others, of all the human rights and fundamental freedoms”

Legal capacity

- The most polemic question
- Introduction of a footnote
- From the replacement model to the assistance model in the decision making
- Replacement model: difference between legal capacity and capacity of acting
- Assistance model: does not differentiate legal capacity and capacity of acting
- The defenders of the second approach, consider that the first one was facilitating the distortion of the desires of the persons, encouraging its absence of responsibility, suppressing its skills and diminishing its growth capacity. The legal capacity, for the assistance model it should be related to freedom, to the possibility of wandering and of being wrong, to the risk, and not to the knowledge, prudence or perfection of the decisions.

Convention: Independent life

- It is recognized the right of all the persons with disability to live in the community assuring especially that:
- a) The persons with disability have the opportunity to choose its residence place and where and with whom to live, on equal terms with the others, and they do not turn out to be forced to live according to a specific life system;
- b) The persons with disability have access to a variety of services of home, residential assistance and other services of support of the community, including the personal assistance that is necessary to facilitate its existence and its inclusion in the community and to avoid its isolation or separation

Convention: deaf community as a cultural minority

- Double perspective : the consideration of the deaf people inside the group of persons with disability and the obligation of the recognition of its cultural and linguistic identity.
 - Art 30 (4): “People with disability have the right, on equal condition, to the recognition and support of their cultural identity, including deaf community and sign language”.
 - Art 24 inc.3 b) establishes the obligation for the States in the Educational field of facilitating the learning of the sign language and the promotion of the linguistic identity of deaf people.
 - When defining “language”, it sets in the same condition oral language and sign language.

Convention implication on Spanish legislation

- Opportunity
 - Change of paradigm
 - The standardization of the disability
- Law and education
 - Legislation: short term but slightly trustworthy
 - Education: long term but trustworthy
- The diversity and the optimistic vision
 - The disability as sample of the human diversity
 - The diversity enriches

Convention implication on Spanish legislation

- LIONDAU and social model. Ratification May 3rd.
- The Constitutional nature of the Convention because of art. 10.2. (Attention in the Spanish Constitution to the new regulation)
 - Political bet
 - Interpretation
 - Progressiveness
- Change of paradigm: social model and legal capacity
- General changes:
 - Freedom and safety
 - Work-employment-services
 - Private law
 - Justice
 - Public services
 - Tributary measurements

Specific implications on Spanish regulations

- Health, health services and investigation.
- Recognition as an autonomous person capable of taking your own decisions. Accessibility of the sheets of information and of the documents of informed assent.
- Clinical essays and treatments respecting its will or its preferences.
- Control of the interventions in the reproductive system.
- Control of the interferences in private and familiar life of the persons with disability, especially in its information relative to their health.

Specific implications on Spanish regulations

- Freedom and safety
 - conditions and treatment of the persons with disability in institutions
 - election of the place of living
 - personal mobility
 - principles that govern the criminal law when the disability is involved

Specific implications on Spanish regulations

- Work-Employment-Social Services
 - protected employment
 - accessibility in the work
 - adoption of reasonable adjustments
 - promotion of self-employment
 - not discrimination at work
 - exercise of labor and trade union law
 - pensions
 - social services

Specific implications on Spanish regulations

- Private regulations
 - Reformulation of the idea of legal capacity
 - Suppression or modification of the process of the determination of competence. Process of reasonable adjustments for the exercise of the capacity or for a process of reasonable support in the exercise of the capacity.
 - Regulation of the personal assistant
 - Review of the adopted measurements from time to time.

Specific implications on Spanish regulations

- Justice, Public Services, Political Participation, Audiovisual Media, Education.
 - Accessibility
 - Better coordination among Administrations
 - Attention to the spare time and culture
 - Creation of specialized Courts
 - Formation of legal operators, officials and professorship
 - Regulation of the figure of the assistants in all fields (especially in schools)

Challenges

- Universal Accessibility
- legal Capacity
- Right to independent life
- Right to the use of sgn language speaking

Challenges: Universal accessibility

- The accessibility is the situation desired, the "design for all" a strategy at general level to reach it and the reasonable adjustments a strategy at particular level, when it has not been possible to foresee the "design for all".
- "Design for all":
 - Art. 2.d) Law 51/2003: "the activity by which it is conceived or planned, from the origin, and whenever it is possible, the environments, processes, products, services, objects, instruments, devices or hardware, in such a way that they could be used by all the persons, in the biggest possible extension"
- Reasonable adjustments
 - Measurements adopted in order to adapt the environment to the specific needs of certain persons with disability. It looks for accessibility in particular cases, but that are adopted when accessibility is not possible from the design for all perspective. Its mission is not to replace the nonperformances of the conditions of accessibility.

Challenges: Universal accessibility

- Universal accessibility as a legal principle
- Right not to be discriminated by accessibility absence
- The right to the universal accessibility
- The universal accessibility as part of the essential content of the rights.

Challenges: Legal capacity

- Art. 12,2 of the Convention: States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- Support model or assistance in the decision making process.
- Need of rephrasing or abolishment of the incapacitation for being an instrument that limits the acting capacity
- Abolishment of the guardianship. Meanwhile, curatorship as a general mechanism.
- In short, same frame than physical disability

Challenges: Legal capacity

- **General regime of legal personality and legal capacity**
 - Person concept. Moment in which the legal protection for a person starts. Any distinction regarding abortion of people with disabilities? How is the rights entitlement legally determined? General regime of legal personality. General regime of legal and acting capacity to practice legal acts or to incur obligations and rights.
- **Incapacitation, interdiction and inhabilitation regime.**
 - Who and how can anyone be declared “incapable”? What is the procedure? On which parameters is incapacity evaluated? What sort of incapacities does legislation allow? Is there the possibility of declaring part-incapacity? What are the legal effects of incapacitation?
- **Institutions of protection and representation**
 - By whom and how are the incapable persons represented? How is the decision making carried out? What acts can the representative make? How is it designated? How is the representation exercise controlled? Do protection institutions exist out of the representation? Protected patrimony, Trusteeships, etc.
- **Early will**
 - Does the actual legislation allow any way of early will? Advanced guidelines preventive power, self-guardianship...

Challenges: legal capacity

- **Capacity to make legal acts concerning patrimony**
 - Juridical effect of the acts made by a person with disability before and after the incapability declaration. Capacity regime for the achievement of hereditary acts?
- **Capacity to make individual legal acts**
 - Juridical effect of the individual acts made by a person with disability before and after the incapability declaration? Capacity regime for the individual acts achievement.
- **Civil responsibility regime**
 - Civil responsibility regime, contractual and extracontractual, regarding the acts made by persons with disabilities. Consequent civil responsibility of the acts made by the caregivers.
- **Penal responsibility Regime**
 - Excuse of penal responsibility or even lack of responsibility of the crimes committed by persons with mental or intellectual disabilities? Over what parameters is the capacity or comprehension judged? What defense guarantees are applicable? Which is the medical imprisonment regime applicable?

Challenges: legal capacity

- Internment regime in psychiatric or medical institutions
 - Does the necessary internment procedure exist in actual legislation? Who can be necessary interned? Why? How do people in institutions access to their rights? What guarantees of physical and psychic integrity do the patients possess in institutionalization contexts?
- Patient rights
 - Is there legislation to regulate the patient rights? And to regulate medical and experimental practices? Is there a different treatment for people with mental or intellectual disabilities? Forced sterilization of people with mental or intellectual disabilities?
- Evaluation of the capacity regarding juridical key acts
 - How is the capacity of the people acting in different legal acts judged? Notarial acts (deeds, minutes...), public official acts (marriage, personal documents processing...), legal officials (witnesses in legal audiences...)
 - Legal capacity in working and trade union relations
 - Contracts and trade union functions

Challenges: Right to an independent living (Art. 19)

- States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community.
- It implies, on the one hand the opportunity to choose their place of residence on equal conditions with others, en igualdad de condiciones que el resto de los ciudadanos (where and with whom they live and are not obliged to live in a particular living arrangement) and, on the other hand, the access to a range of in-home, residential and other community support services, (among others, domestic, residential and personal assistance)

Challenges: Right to an independent living (Spanish law 39/2006)

- Right to personal autonomy and attention of people in dependence situation: Right to universal titularity that guaranties a group of provisions and services.
- It is compounded, besides of the right to have every right in the actual legislation, of a group of financial provisions (services, familiar support or personal assistance) and service provisions (prevention, tele-assistance, home support, Day and Night Centers, and residential Support)
- It is integrated in the SAAD (Autonomy and Dependence System), and it depends on the dependence grade that has the person, what demands the existence of a report from the Administration that defines the services or provisions for the person.

Challenges: Right to an independent living

Differencens among the rights

- The basic difference between the right defined in law 39/2006 and the right defined on the Convention, is that the first one is not targeteed to autonomy, but to protect people in a dependence situation.

Challenges: Right to an independent living

Dependence situation

- Law 39/2006 defines dependence: “the permanent state in which there are the persons who, for reasons derived from the age, the illness or the disability, and tied to the absence or to the loss of physical, mental, intellectual or sensory autonomy, need the attention of other persons or important helps to achieve basic activities of the daily life or, in case of the persons with intellectual disability or mental illness, of other supports for their personal autonomy”.
- This definition associates dependence with specific groups of people.
- It seems appropriate to use a definition of dependence that gives more importance to the “situation” rather than the belonging to an specific group.
 - The “dependence situation” is not a merit of some people, but a situation that affects –temporarily or not- some people in some moments of their lives.
 - There is no such thing as “dependent persons” and “independent persons”, but situations in which a person can loose or get a limit in his/her autonomy for the achievement of some activities.

Challenges: Right to an independent living

Basic activities on our daily life

- Law 39/2006 defines dependence situation as the one that has a person that needs help to achieve some basic activities on his/her daily life. These are defined as “the more elementary tasks for a person, which allow him/her to be unrolled by a minimum of autonomy and independence, such as the personal care, the basic domestic activities, the essential mobility, acknowledge persons and objects, orientate, understand and execute orders or simple tasks”.
- The dependence situation has a limited frame, that needs to be wider, including:
 - instrumental activities (more complex activities that require a bigger autonomy and that are united to tasks that require decision making and more difficult interactions with the environment)
 - Specially complex and elaborated activities that are related to the control of the physical and social environment, that allow the person to develop a social role, keep a satisfactory mental health and an excellent quality of life (Advanced activities).

Challenges: Right to an independent living

Accessibility

- Universal accessibility is presented as a necessary condition for the exercise of the rights on equal conditions with others for everyone.
- It is projected in situations that exceed the ambience of the Law and that are regulated in other normative dispositions. But in any case, in the Law 39/2006, it must have a transverse projection in all the services and services that it contemplates.
- Besides, the importance of the accessibility, has a concrete projection that demands the enlargement of the catalog of services and provisions, through the recognition as a subjective right of the “Economic aids to facilitate the personal autonomy”, in its double coverage of acquisition of technical helps or instruments necessary for the normal development of its everyday life and access to information, and simplification of the accessibility and adaptations at home and in the immediate environment.

Challenges: Right to an independent living

Residential provisions

- The institutionalization is seen with caution in the Convention. The admission in an open center of a person with disability will be able only when assent has come up, and only exceptionally and with the due legal and judicial guarantees the involuntary institutionalization can be ordered.
- As in the Convention, the Law 39/2006 suspects of this point, since one of the principles that inspire it, "assignation", means the permanence of the persons in dependence situation, whenever it is possible, in the environment in which they develop their lives.
- In any case, in the achievement of these services the rights of the persons will have to be respected meticulously in dependence situation.

Challenges: Right to an independent living

Familiar caregiver

- Knowing that it would be necessary to recognize the freedom of the person in dependence situation to choose where, how and with whom to live, it would be convenient to create a specific juridical article for the informal caregiver with the intention of removing the obstacles that make difficult the worker that freely decides to attend a relative, to assume this care task. In this respect, this regulation must pay special attention to the labor situation of the caregiver and to its social protection.

Challenges: Right to an independent living

Personal Assistant

- The personal assistant is provided in article 19 of the Convention, and in articles 2 and 19 of law 39/2006
- Anyway, in the law, the provision is restricted in comparison to what is settled in the Convention, referring the activities that it covers: education, work and basic activities of the daily life. For the persons that have access to the provision – it is limited to the people that have “big dependence”
- It is necessary to extend the economic service of personal assistance so that those persons in situation of dependence could receive it, despite of the grade recognized, as they need it and, also, that not only it is destined for the access to education and for the employment, but to cover all the areas of development that implies the plan of personal life.
- It is necessary to establish a regulation of this person, by handling an integral assistant concept (who makes the work as regards the wide vision of the fundamental activities of the daily life) or several assistants' models, depending on the concrete activity done.

Challenges: Right to an independent living

Equality

- In view of the Convention and the equality demand, the State must establish a few norms that guarantee, at least, the homogeneity in: (i) the procedure of recognition of the situation of dependence; (ii) the professional profile of those who value the dependence situation; (iii); the regulation of the procedure to determine Individual Attention Plan; (iv) the criteria of contribution of the user in the cost of the service (in case it was necessary); (v) the incompatibilities.

Challenges: the right to use the sign language speaking (law 27/2007)

- The right to use the sign language speaking and its relations with support measures
 - Freedom to choose
 - Non-discrimination
- Interpreters and interpreter guides
- Education
 - Inclusive
 - Sign language