



**DISABILITY AND
INCAPACITATION: MOVING TOWARDS
A CHANGE OF VISION.**



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INTRODUCTION: THE CONVENTION

The purpose of this paper is to convey an overview of the current situation of people with intellectual disabilities in Europe. In principle we assume that the field of services for intellectually disabled people in Europe, its problems, strengths, rights and opportunities for development can only be understood if one is familiar with the pathways that led to the current regulation.

In the past, there was a world-wide conception of disability -mental and physical alike- as a person or a family's misfortune, and even as a "divine punishment" in many cases. This served as some what of an excuse to society's tendency to marginalize persons with different capacities; marginalization which of course responded to a fear of the different, a stigma of what society cannot understand. This discrimination, which has widely evolved but still resonates today, reaches all aspects of life in a society: employment, health services, education, reproductive rights, abortion, right to vote, access to public spaces and services, ICT, housing, etc. All this leads to an economical, social and professional disadvantaged position for people living with a disability, which in turn makes society, almost automatically, view them as second-tier citizens. People living with disability have a higher risk of poverty and social exclusion (28.4% according to the Eurobarometer 493¹, versus a 18.4% for people without disabilities). In the last few decades, there has been a general social movement of inclusion, of acceptance of diversity in the human condition, through many different aspects: anti-racism, LGTBIQ+ movements, etc.

¹ Special Eurobarometer 493, Discrimination in the EU, May 2019.

In respect to the fight against ableism², the Convention of the Rights of Persons with Disabilities (hereon, the Convention) drafted by the United Nations in 2006, and ratified by 163 countries, has meant a change in the perspective of disability, at an international level, but also forcing a change in national disability law. Most Signatories have already proceeded to renew domestic disability legislation, as well as laid down National Monitoring Mechanisms in order to keep updating these laws, as prescribed by the Convention. The Convention has therefore meant not only visibility for people with disability as a group, but also a powerful tool in the fight for recognition of their rights.

The start of the international discourse leading up to the drafting of the Convention can be located in the Experts Meeting of 1987, charged with examining the application of the World Programme of Action³, arising the first real occasion to create an international document to protect the rights of persons with disability. Still, it was not until 2002 that the Committee for the Rights of Persons with Disability was constituted, to start drafting the Convention, after eight meetings concluding in December of 2006.

At a European level, the (98)9 Recommendation of the European Council used to be the fundamental text for the European countries to follow on this matter. Also relevant was the (94)9 Recommendation about the rights of older citizens, and of course the European Social Charter, specifically article 15: *“disabled persons have the right to independence, social integration and participation in the life of the community”*. However, this legislation was insufficient, seeing as the mechanisms of protection for first-generation economic, social and cultural rights were more profound and effective than this specific one (especially because these initiatives for social cohesion were mere recommendations).

Nevertheless, the European Council expresses a special sensitivity on the matter of dependency, as the European continent faces the challenge of an

²Ableism refers to the discrimination and social prejudice against people with disabilities and/or people who are perceived to be disabled

³ The World Programme of Action (WPA) is a global strategy to enhance disability prevention, rehabilitation and equalization of opportunities, which pertains to full participation of persons with disabilities in social life and national development.

increasingly ageing population, with urgent needs and fundamental rights to be considered and protected.

DISABILITY AS A PART OF THE HUMAN CONDITION

The Convention on the Rights of Persons with Disabilities, in its article 1, states as the purpose of the Convention “*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*”. To analyze what this really means, it is only right to start by exploring the concept of dignity itself. In modern democracies, the fundamental rights of citizens are based on the idea that each individual has value, not because of -but independently to- the role they play in society; just for existing, and beyond their personal characteristics (race, sex, age, social position) and, of course, their capacities.

This seems to undermine the utilitarian concept that people are more valuable the more they produce, the more they intervene in the society they live in. However, societies and institutions -especially in the work market, logically- tend to value people in that way, even if social sciences have generally moved away from of this idea, especially following Kant’s basic rule that human beings should be treated as an end in themselves and not as a means to something else.

Furthermore, we cannot ignore “*the fundamental role the Enlightenment played in the configuration of the idea of rights and their guarantees*”⁴(Asís, 2007⁵). The idea of human dignity that this cultural movement established was inherently linked to a person’s physical and moral attributes, insofar as it was meant to protect their integrity. It consequently constructed an idea of a paradigmatic, or “ideal” individual, which excluded certain groups, especially people with different capacities.

Thankfully, since the beginning of the XXI century, the study of disability has followed a tendency to view disabilities no longer as a “sickness” or “handicap” certain persons have, but rather as the barriers they find when

⁴Translated from the original.

⁵ De Asís, Rafael: “*Derechos humanos y discapacidad. Algunas reflexiones derivadas del análisis de la discapacidad desde la teoría de los derechos*”, 2007/01/01, Universidad Carlos III de Madrid.

socializing with others. The Convention includes this concept of disability in its Article 1, and the Spanish 2020 Project of law to modify civil legislation, in its Preamble, explains that “many of the limitations traditionally linked to disability have not come from the persons affected by it, but from their environment: physical, communicative, cognitive, behavioural and legal barriers”⁶. This perspective change is due to what social doctrine calls “the social model” of disability, versus the “medical model”, which used to put the attention on the mental and physical “shortcomings” of certain people.

Due to this paradigm change, the study and, more importantly, the fight for the rights of persons with disability has now become a global issue. That is, it concerns not only people with disabilities and their families, but the society as a whole. The success of the social model is explaining disability not as the abnormality of a subject, but the abnormality of a society towards its own diversity.

RIGHTS OF PERSONS WITH DISABILITY AS A QUESTION OF HUMAN RIGHTS

The rights of persons with disabilities are a question of human rights. Although this point is scarcely questionable, especially taking into account the aforementioned Article 1 of the Convention, it is worth highlighting the specific human rights which are in question when we talk about this issue.

Even though it is a transversal matter, affecting all aspects of life, we consider that the fundamental rights directly at stake here are the following: equality, integrity (as the interdiction of degrading treatment) and liberty (including the free development of the personality). These rights are all recognized in the International Treaties of human rights⁷ as well as in the Constitutions of the European countries⁸.

⁶Translated from the original.

⁷Equality (UDHR, article 1; ICCPR article 26, ECHR article 1); Integrity and Dignity (UDHR article 5, ICCPR article 7, ECHR article 3) and Liberty (UDHR article 3, ICCPR article 9; ECHR article 5).

⁸ As an example: Basic Law of the Federal Republic of Germany articles 3 and 2 respectively, the Austrian Constitution articles 2 and 8; Italian constitution article 3.

The Convention, as a first international treaty on the matter, acknowledges that: “*impairment may not be used as a justification for denial or restrictions of human right.*” (Degener, 2016). The emphasis on this issue as a question of human rights demonstrates the obligatory nature of a legislation protecting these rights unconditionally, at least in a society that considers itself a Democracy, and encouraging society to abandon the relegation of thousands of their compatriots.

PRINCIPLES WHICH UNDERLIE THE CONVENTION (AND THEREFORE INFORM THE LEGISLATION)

One of the principles behind the international legislation of disability issues is what scholars call “moral liberty”, which is more or less what we usually call autonomy. The concept of autonomy, or the self-governance of a person, should not be confused with the concept of being independent. The first refers to the possibility of making one’s own decisions, designing therefore one’s life plan; while independence refers to the capacity to fulfil those plans. That is, to carry out daily functions without the need of help (a concept which needs to be played down, given that we are social beings and need daily assistance of others). A Spanish law back in the year 2003 explained the principle of moral liberty very clearly as “*the situation in which a person with disability exerts the power of decision over their own existence and participates actively in the life of their community, following the right to the free development of personality*”⁹.

To be effective, the principle of moral liberty requires, firstly, a legal liberty to lead one’s own life. This includes, of course, the private aspects of life (freedom to manage our economy and patrimony, our professional ventures, and chose to form a family) and the participation in public life (especially political participation in a democratic system, as well as access to public employment and services). The fact that some people need special support to carry out certain tasks -such as ramps to access a building, or the use of easily comprehensive language to understand a legal text- is not equivalent to saying these people cannot participate “as valuably” or “as much” as others. Diversity in a society means the ways of interacting among us must be diverse as well.

⁹Translated from the original. Law 51/2003 of December 2nd: *igualdad de oportunidades, no discriminación y accesibilidad universal de las personas con discapacidad.*

As well as this, the principle of moral liberty requires a big modification of the incapacitation process, not understanding it as an instrument to cancel all their rights and “capacity to act” in an almost automatic way. This is what jurisprudence (by the European Court of Human Rights, as well as by the national courts of several European countries) has named “the tailor-made suit”. This means the sentences of incapacitation should be as varied as the infinite limitations different people experience in their daily management. It should therefore be essential for the court to examine each case closely and individually, to give a personalized answer to the support mechanisms each person will need throughout their lives.

The Preamble of the Project of law to modify civil legislation on the matter in Spain goes further, stating “*a judge can not modify a capacity which is inherent to the human condition*”. Therefore, today the Spanish legislator understands “incapacitation” not as the modification of this capacity but merely as the adaptation of the way to carry it out.

Lastly, the principle of moral liberty requires a reinforcement of tutelage mechanisms, which centres on representation more than guardianship. Currently, Spanish civil law is pivoting towards this kind of system, as we will explore later.

NUMBER OF INCAPACITATIONS IN EU MEMBER STATES

Germany. For those persons described as “intellectually disabled,” the term *geistige Behinderung* has become normal usage in German¹⁰. Current definitions of intellectual disability try to avoid the controversy a few years ago in Germany between psychiatrists, educators, and lawyers about the proper meaning of this term. The different concepts refer to the legal status of people with intellectual disabilities and their eligibility for benefits. It is characterized by intelligence or mental capacity with special circumstances and a lack of skills necessary for day-to-day living.

¹⁰Intellectual Disability in Europe. *Working papers*. European Intellectual Disability Research Network. March 2003.

German regulations abolished the traditional institutions of judicial incapacitation (“Entmündigung”), guardianship of adults (“Vormundschaft über Volljährige”) and guardianship (“Gebrechlichkeitspflegschaft”), replacing them with the term “assistance” (“Betreuung”) sections 1896 to 1921 of the new German Civil Code (BGB). It is the most radical European reform on the matter.

In the case of physical disability, and in terms of active legitimation, the support request can only be submitted by the interested party. However, if it affects the formation of a free capacity for self-determination, the “Betreuer“ can also be designated against the will of the interested party, since it is considered that the will cannot be considered free when the person cannot benefit from the advantages that would derive from the “Betreuung.”

Statistics about the situation in Germany are imprecise. However, in their “Berlin Memorandum,” the four leading professional associations estimate that there are currently approx. 420,000 intellectually disabled people in the Federal Republic of Germany, approximately 185,000 juveniles and 235,000 adults. Approximately 85 percent of the intellectually disabled juveniles (approximately 160,000) live with their families.

An update of the national statistics for Germany at the end of 2019 showed approximately 7.9 million people with severe disabilities. The Federal Statistical Office (Destatis) also reports that this is an increase of approximately 136,000, or 1.8%, compared to 2017. Furthermore, to mark Germany’s Diversity Day on 26th May 2020, the aforesaid office reported that “in 2017 the proportion of persons in employment and job-seekers among people with disabilities was 30%, less than half that among people without disabilities (65%)”¹¹.

France. In France, the legal concept of “judicial safeguarding or protection” is used very frequently in practice as a temporary measure (limited to a two-month period, with unlimited semi-annual renewal). It is intended for temporary situations or as a transitory measure prior to the appointment of a

¹¹https://www.destatis.de/EN/Themes/Society-Environment/Health/Disabled-People/_node.html. D-STATIS Statistisches Bundesamt reports comply with the standards of the European Statistical System (ESS) and the European Statistics Code of Practice.

guardian or tutor (*curatelle*). It applies to those of legal age who need to be protected in their activities in civil life due to mental or physical impairment. However, there must be some effect on mental capacity or, at least, on the possibility of external manifestation of their will, without reaching the point of needing an assistance or representation regime. In this case, under the former article 491-2 of the Civil Code: “*The person of legal age placed under the safeguard of justice preserves the exercise of his or her rights*” implying that the person is not incapable.

France’s Civil Code explicitly establishes that actions by the person subject to such measure must be controlled not *ex-ante*, but afterwards, execution (art. 491-2), although it is possible to appoint a special agent for a certain action or a series of actions (art. 491-3).

This system of protective measures has been partially reformed by Law 308 of 5th March 2007 *On the Protection Of the Elderly* (which came into force in January 2009), which introduced several new features in the Civil Code. These included a gentler legal wording (“protect the weak but never diminish them”; “the world of vulnerable persons”) than in the previous one (“incapacité”; “contrôle”; “gouvernement de la personne”), and encouragement of social assistance for the person in need of protection against guardianship and deprivation of their rights.

Likewise, the 2007 Law introduced the future protection mandate (“mandat de protection future”), inspired by Québec’s disability mandate and in the style of Spain’s preventive mandate contemplated by the LPPD (Civil Code, article 477).

In 2019, according to data from INSEE (National Institute of Statistics and Economic Studies), 5.95 million of the French population between the ages of 15 and 64 years old had a disability. It seems, when compared by gender, that this figure was higher for women than for men: the population with disabilities included 2.75 million men, compared to 3.2 million women.

United Kingdom. Although this country is outside the European Union (as a result of the Agreement on the withdrawal of the United Kingdom of Great Britain and Northern Ireland from the European Union and the European Atomic Energy Community (2019/C 384 I/01. Article 50 of the Treaty on European

Union)), there follows a brief analysis of its situation. There are two figures: the “trustee” of the disabled person’s assets and the “deputy” for the person’s personal care, both appointed by the Court of Protection. At the same time, there is also an explicit discipline regarding the voluntary representation of the incapacitated person in anticipation of an eventual future incapacitation, the Durable Power of Attorney.

The White Paper (Department of Health, 2001) estimates that while in 1971 there were 24,500 places in Adult Training Centers, in 2001, there were 84,000 adults with learning disabilities receiving community-based services. These services include home help, meals and nursery care. Of these, 49,600 were in receipt of social services day services (many in adult training centers), with 6,630 patients using NHS day care facilities. Most of the information on the prevailing service models comes from the research literature rather than official publications from the local or central government.

However, an update of the information on the official UK statistics shows that there are currently 1.5 million people with a learning disability. The figures have been calculated using prevalence rates for learning disabilities from Public Health England (2016) and population data from the Office for National Statistics (2019).

About 2.16% of UK adults are believed to have a learning disability. Approximately 2.5% of children also have a learning disability. This represents 351,000 UK children aged up to 17 with a learning disability. Within that age range, 118,000 children between up to 5 years have a learning disability¹².

Austria. Austrian Law 136/1983, of 2nd February, *On the Guardianship of People With Mental Disabilities*, which came into force on 1st July 1984, broke with the traditional system of judicial incapacitation and created a completely new one, not only in that country but in the western Roman legal tradition. This system is based on the figure of a guardian (Sachwalter). A Sachwalter’s role must be established, with great precision, “by the judge” in each specific case (article 273

¹²Mencap. The **Royal Mencap Society** is a charity based in the United Kingdom that works with people with a learning disability. <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability>

Allgemeine bürgerliche Gesetzbuch¹³, identified as ABGB in this paper) and always based on the degree of the person's mental (not physical) illness"¹⁴.

The *Sachwalter's* role varies, as its scope can cover a single matter, for a specific category of affairs, or all the interests of the person assisted. It has to be established with great precision by the judge in each specific case (article 273 of the ABGB). It is always based on the degree of mental illness (which differentiates it from the Italian figure of the support administrator) of the person unable to manage, without danger or damage, their affairs, and they do not have the possibility of being assisted.

This means that persons subject to the *Sachwalterschaft* do not lose their capacity in those parts of their lives not affected by the judicial decision. They can get married or make a will (before a judge or notary) as long as they are able to understand and are willing. In addition, they have the right to participate in the most important decisions that concern them (ABGB article 273 a, paragraph 3). It is, therefore, a very flexible system that allows for the person's social inclusion (mainly achieved by excluding active legitimation of other subjects and restricting publication of the procedure). The person retains their ability to act in the area in which they are most well-known, sacrificing their freedom as little as possible. As such, the Austrian system, like the German, is more advanced than the French¹⁵.

To summarise the most recent official statistics about disability in Austria, the most common permanent disabilities mentioned in a 2015 survey¹⁶ were due to mobility problems. A projected total of around 1 million people, or about 14.1% of the Austrian population over the age of 15 in private households, were affected. Furthermore, 7.3% of the population reported more than one disability; that corresponds to around 534,000 people with multiple permanent disabilities. In addition, 374,000 persons (5.1%) had other disabilities than those indicated

¹³ ABGB is the General Civil Code of Austria. Consolidated federal law: Entire legal provision for the General Civil Code, version dated June 12, 2021.

¹⁴ Overview of the horizontal issue of disability in Austria, publishing by the Federal Ministry of Social Affairs, Health, Long-term Care and Consumer Protection. Mag. Johann Döllner, Mag.^a Mariella Beier, MA, Vilmos Nagy. Vienna, April 2020, from page 10 onwards.

¹⁵ *Living with Disabilities in Austria – With a Special Focus on the Capital*. Alois Soritsch.

¹⁶ Overview of the horizontal issue of disability in Austria, publishing by the Federal Ministry of Social Affairs, Health, Long-term Care and Consumer Protection. Mag. Johann Döllner, Mag.^a Mariella Beier, MA, Vilmos Nagy. Vienna, April 2020, from page 6 onwards.

within the survey framework. With around 270,000 affected persons (3.7%), nerve-related or psychological problems were the third most common. In fourth place were problems with vision (3% or around 216,000 persons), and somewhat fewer indicated problems with hearing (2.1% or around 157,000 persons). Mental problems or learning difficulties affected 0.8% of the population (around 60,000 persons), and 0.4% had problems with speaking (around 26,000 persons).

Italy. Italy has adopted the legal figure of the “Support Administration” by Law No. 6/2004¹⁷. Through this Law, of extraordinary ethical-social relevance, a radical change takes place in content, concepts, and terminology. The Law responds to a motto or slogan: “nothing about us without us.” This means that all decisions that concern non-autonomous persons must be taken through prior consultation with them, fully involving them in the decisions and taking into account, above all, their real demands and needs, so that they themselves are really the focus of disability policies.

There are an estimated 3.2 million Italians with disabilities, including 2.5 million elderly. The proportion of women is higher than that of men: 7.1% to 3.8%. In more than half of the cases (55.5%), people have multiple functional problems (1.8 million seriously disabled). At the same time, approximately 540,000 are aged under 65, and most of them live in the south of the country.¹⁸

Spain. Spain has two different concepts: *discapacidad* (disability or sick leave) and *incapacidad* (incapacity to work). Together, these refer to a person’s inability caused by injury or disease that limits their daily life in the social or personal sphere or at work. This conceptual classification takes into account the importance of two documents. The first is the UN Convention on the Rights of Persons with Disabilities (CRPD). The other is Spain’s Royal Legislative Decree 1/2013, of 29th November, approving the Consolidated Text of the *General Law on the Rights of People With Disability and Their Social Inclusion*. This law consolidates three other laws related to social integration, equal opportunities and infractions and sanctions. However, this similarity in names does not mean that both concepts are the same. Statistics from the National Statistics Institute

¹⁷Law 09.01.2004, No. 6. Italian OJ 19 January, No. 14, 2004. Available at: <https://www.gazzettaufficiale.it> [last viewed October 16, 2019].

¹⁸This data was reported in a recent publication by the Italian Institute of Statistics (ISTAT).

(INE) show that in 2015 Spain had 3.85 million persons with a disability (59.8% women). Statistics¹⁹ from the National Social Security Institute (*Instituto Nacional de la Seguridad Social*, INSS) show a heavy caseload for workers on temporary sick leave. In response, both concepts have been updated: about disability leave, Law 39/2006 altered the terminology to avoid concepts with discriminating or pejorative connotations, and about sick leave, there is a new Law:8/2015, 30th of October, General Law on Social Security)²⁰.

According to the National Disability Survey, in 1999²¹, 134.468 people had mild to severe disabilities. That estimate represents 0.33 % of the population (40 million people). This is a general record of all legally handicapped people (last update in Spain: October 2009). This record includes 144.331 cases with intellectual disability (0.36% of the population). This represents 11.5% of all registered disabled people (14.1% males; 9.2% for females). The age distribution is as follows: 14 years or under, 44.8%; 15-34 years, 27.0%; 35-64 years, 5.7%; over 64 years 0%. Intellectual disability is the main type of disability in children. 63% of mental disabilities are of unknown origin, while the cause is known in 37% of cases. Down's syndrome is the most frequently diagnosed cause (12% of cases, 54% male), followed by infectious brain diseases (e.g. meningitis and encephalitis) (10% of cases, 53% males). The national database does not record cases with mild impairment (below 33% in the official classification table) or those who have not applied for legal handicap status. The lack of cases above 65 years of age reflects the problem of this data system.

The most recent official disability statistics for Spain, published by the National Statistics Institute (INE) in May 2015, indicate that 3.85 million people declare they have a disability, and 59.8% are women. Disability rates by age are slightly higher in men up to 44 years of age, and above 45, the situation is reversed; this difference grows with increasing age. However, women have a significantly higher disability rate per thousand inhabitants (106.3) than men

¹⁹The National Institute of Statistics (INE in Spanish) plans to publish in 2021 a new survey 'Disability, Autonomy of People and Dependency Situations', to update data on people with disabilities in Spain, since the last study was published in 2008/2009 with figures for 2007.

²⁰ All this related to the recent publication of Law 8/2021, 2nd June, which reforms civil and procedural legislation to support people with disabilities in the exercise of their legal capacity.

²¹ INE (National Statistics Institute): Overview of disability in Spain. Surveys on Disability, Personal Autonomy and dependency situations. 2008.

(72.6). By disability group, the highest rates for women are for mobility (77.5), domestic life (69.2) and self-care (55.3). In men, the highest rates correspond to mobility (42.6), self-care (31.3) and domestic life (29.5).

FORCED STERILISATIONS, ABORTION AND RIGHT TO VOTE

It is now important to deal with some specific issues affecting persons with disabilities. As mentioned above, the Convention was approved in 2006 and subsequently ratified by Spain, entering into force in 2008. The Convention includes a series of articles on the rights of persons with disabilities concerning forming a family, a home, being parents and their personal relationships. Hence, it is only fitting to start this section by bringing up article 23 of the Convention, which states:

“1. States Parties shall take effective and appropriate measures [...] 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[...]; (c) Persons with disabilities, including children, retain their fertility on an equal basis with others.”

Focusing on the topic that concerns us here, which is forced sterilisations, these are expressly prohibited by article 39 of the Convention on Preventing and Combating Violence against Women and Domestic Violence, in force in Spain since 2014. It says that *parties shall take the necessary legislative and other measures[...] to ensure that [...]surgery which has the purpose or effect of terminating a woman's capacity to naturally reproduce without her prior and informed consent or understanding of the procedure, are criminalised.*

It follows from the above that the above-mentioned international treaty does not allow forced sterilisations. Hence, it is at the very least surprising that Spain allowed them until the Organic Law, 2/2020, of December 16th, *On the Reform of the Criminal Code for the Eradication of Forced or Non-Consensual Sterilisation of Judicially Incapacitated Persons With Disabilities*, which came into force 17th December of 2020. Until then, forced sterilisations were regulated by the second

paragraph of article 156 of the Criminal Code, in the wording given by Organic Law 1/2015, of March 30th:

[...]. However, sterilisation of an incapacitated person agreed by a judicial body shall not be punishable in the case of people who, in any way and permanently, cannot give the consent referred to in the preceding paragraph, provided that they have to be exceptional cases in which there is a serious conflict of protected legal rights, in order to safeguard the best interest of the affected, all in accordance with the provisions of civil law”.

Outlawing forced sterilisations constitutes, subsequently, compliance by Spain with the International Conventions mentioned above. This change has taken over ten years to happen. It means that reasons like “the welfare of a family”, “the inability of women with disabilities to be mothers,” or that it is regulated that way for “the sake” of people with disabilities are no longer considered.

However, despite all the above, and until recent legislation outlawed forced sterilisations, more than a thousand were carried out (data from the Spanish General Council of the Judiciary).

Another point, no less important, is possible discrimination in abortion regulation in Spain, under Organic Law 2/2010, of March 3rd, *On Sexual and Reproductive Health and Voluntary Pregnancy Termination*.

Organic Law 2/2010, in article 5.1 (d), contemplates as one of the government objectives the challenge to eliminate all forms of discrimination, with particular attention to people with any disability, who shall be guaranteed their right to sexual and reproductive health. For this, the necessary support measures have to be established, taking into account the specific demands of each and all persons with disabilities. The point is that we can deduce from this purpose the intention there is of protecting the mother from a possible disability. However, it never mentions the disability the unborn child may have.

Furthermore, the aforementioned Organic Law contemplates exceptionally, apart from the general rule in which the abortion can be practiced within the first fourteen weeks of gestation as long as it is a free and informed decision, as the

medical causes for interrupting pregnancy, in article 15: “a) *That the twenty-two weeks of gestation are not exceeded, as long as there is a serious risk to the life or health of the pregnant woman [...]; b) That the twenty-two weeks of gestations are not exceeded, as long as there is a risk of serious abnormalities in the foetus and this is stated in a medical opinion issued prior to the intervention by two specialist doctors other than the one who leads it; c) When foetal anomalies incompatible with life are detected and this is stated in an opinion previously issued by a specialist doctor, other than the one performing the intervention, or when an extremely serious and incurable disease is detected in the foetus at the time of the diagnosis and is confirmed by a clinical committee.”*

The first of the medical causes stated (a) is justified in the Preamble of the Organic Law 2/2010, based on the legislator's obligation to consider the protected legal rights at stake. Even though judgment 53/1985 of the Constitutional Court of Spain considers the *nasciturus* as a protected legal right, in this specific cause, the right to life and health of the pregnant woman is considered to prevail.

However, the second postulation seems as though it is based on the risk of the possible disability of the foetus. Thus, it appears that lawmakers do not protect the life of the unborn child with risk of disability to the same extent as the life of the unborn without such risk.²² This is because the requirement for an abortion to be carried out after week fourteen and before week twenty-two is precisely the existence of such disability.

On the other hand, (c) covers two different justifications for regulated abortion, none of which are subject to anytime limit. The first one, foetal anomalies incompatible with life, does not pose significant problems since if there is no viability for life, there is no legal right to protection. Nonetheless, the same does not occur with the second reason: severe and incurable disease. In this case, there is viability to live outside the pregnant mother's womb, and therefore it should be entitled to legal protection. Despite this, it is not considered a valid argument for legislators, who allow abortion to be carried out as long as the aforementioned class of disease is diagnosed.

²²Echenique-Robba, Pablo (2013). El aborto y la discapacidad (*Abortion and disabilities*). El Diario.

All the above provides a glimpse of the disdain for human life when it comes to a foetus that could have some kind of disability. This disdain further demonstrates the existence of discrimination by not treating equally or with the same value prenatal life with or without a disability.²³

In conclusion, associations, like the Spanish Down's Syndrome Federation²⁴, state that defending so-called eugenic abortion to avoid the birth of a person with disabilities is equivalent to arguing that life is inferior in value to that of a person without any disabilities, and therefore a less favourable treatment is legitimate, since a disability is a specific aggravated cause included in the regulation for allowing an abortion.²⁵

All of this is therefore contradictory to the Convention, which establishes in its first article that its purpose is to "*promote, protect and ensure [...] the rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.*" Hence, it is an obligation on all party states to adopt real and effective measures to protect the right to life of all people, in fulfilment of Article 10 of the Convention.

With that in mind, it is appropriate here to discuss the right to vote of judicially incapacitated persons. Focusing on the Spanish regulation of this matter, article 3 of the Organic Law of the General Electoral Regime denied the right to vote to those declared incapable (in a final judgement, provided that it expressly declared the incapacity to exercise the right to vote) and of those interned in a psychiatric hospital with judicial authorisation, during the period of their internment (provided that in the authorisation the Judge expressly declared the incapacity to exercise the right to vote). In addition, it stated that the judges or courts hearing a case of incapacitation or internment procedures had to expressly pronounce on the inability to exercise the right to vote.

²³Paredes, Agustina (2010). ¿Por qué el aborto eugenésico basado en discapacidad es contrario a la Convención Internacional sobre los Derechos de las Personas con Discapacidad? (*Why is eugenic abortion based on disability contrary to the International Convention on the Rights of Persons with Disabilities?*). Revista Síndrome de Down.

²⁴Marín, Carlos (2009). Aborto y discapacidad (*Abortion and disability*). Serie: documentos DOWN España.

²⁵Arnau Ripollés, Soledad (2012). El aborto eugenésico (*Eugenic abortion*).

However, Organic Law 2/2018, of December 5th, for the modification of the Organic Law 5/1985, of June 19th, of the General Electoral Regime to guarantee the right to vote for all persons with disabilities, in force since the 7th of December of 2018, repealed points(b) and (c) and the second paragraph and inserted:

“Every person will be able to exercise their right to vote actively, consciously, freely and voluntarily, whatever the way they communicate it and with whichever means of support they require.”

Hence, the aforementioned Organic Law 2/2018 complies with article 29 of the Convention, which governs the right of persons with disabilities to participate in political and public life, compliance that has taken over four years to become a reality. This change means that all State Parties of the Convention have to guarantee this right to allow all members of society to enjoy it on an equal basis.

AFFIRMATIVE ACTION

Discrimination can be expressed in many ways. And this was precisely one of the obstacles that the pre-Convention legislator found when it came to setting the prohibitions and protections they deemed necessary. In this respect, the fight for women’s rights has been indeed useful, having the European Court of Justice defined the parameters of direct and indirect discrimination, as well as ratifying the validity and the need for “affirmative action”; which means actions destined to avoid or compensate inequalities. In the Spanish case, the basis of this affirmative action is found in its Constitution, in its article 9, section 2: *“It is incumbent upon the public authorities to promote conditions which ensure that the freedom and equality of individuals and of the groups to which they belong may be real and effective, to remove the obstacles which prevent or hinder their full enjoyment, and to facilitate the participation of all citizens in political, economic, cultural and social life.”*

With some limitations, affirmative action has been accepted throughout the European Union, and countries have adopted a great variety of measures. A very habitual example is the quota set by many countries (such as Spain, Portugal, France or Germany) wherein an employer is required to hire a certain percent of

workers with some kind of officially recognized disability. This quota system (which is usually complemented with tax benefits) began in Europe and has extended to many other countries. Nevertheless, some countries like Sweden, Finland, Denmark or Norway understand the quota system as unfair, and opt for different measures aiming to persuade employers to offer employment opportunities to persons with disabilities.

Other affirmative action examples include reserving certain unqualified jobs to people with disability, a quota also in the access to public employment, measures to protect workers against discrimination inside the workplace (especially regarding harassment and promotions) and improving educational opportunities (giving some people more time to fulfil official examinations, creating special courses in Universities directed towards people with mental disabilities, or establishing preferences in the access to ordinary courses, for people who fulfill the general requirements to get in).

Today, the legal instruments which inspire this affirmative action measures are the European Disability Strategies, prompted by the European Pillar of Social Rights. But before these were created, there was already an obligation for European Countries to eliminate the barriers which lead to discrimination. Firstly, article 19, section 1, of the Treaty on the Functioning of the European Union states: “(...) *the Council (...) may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.*”, complementing the obligation to fight against all discrimination based on disability in the definition and execution of its policies and action, stated in its article 10. Furthermore, article 26 of the EU Charter of Human Rights declares: “*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.*”, following up the prohibition to all discrimination based on disability expressed in its article 21.

With basis on this principles set by the primary treaties of the Union, there was a Directive in the year 2000²⁶, whose article 7 affirmative action by the States. It is remarkable that only three European countries (Sweden, Ireland and the United Kingdom) had specific laws regarding discrimination based on disability before this Directive came to be. This Directive began the process of concrete legal measures of adaptation between the European society and the persons with different capacities, even if legal action by the States was not immediate, and far from perfect, of course. In many cases, countries were taken to the European Court of Justice for not having a legislation complying with this Directive: specifically Greece, Luxemburg, Austria and Germany. Some countries –like Italy, Greece and Luxemburg- had legislation which was too generic, and in some cases a mere copy of the Directive’s text, which impeded the practical application of the Directive, and does not satisfy the need to further develop particular aspects of it. However, some countries went beyond the obligation to the protective measures on employment, including reasonable adjustments to other aspects of daily life, such as public transport.

CONCLUSIONS

- I. There has been a change in the way our modern society perceives disability and people with disabilities, which today centres around the barriers that hinder their full and effective participation in society.
- II. This change in the conception of disability from a medical model to a social model has led to a change in legislation in most European countries, following the paradigm of the Convention.
- III. Taking away the rights of persons with disabilities comes more from misunderstanding them than from seeking to help them. This argument is corroborated by the fact that there are more incapacitated women than men and more children than adults. That is, the more prejudice or misunderstanding there is towards a group, the more readily they are deprived of their rights.
- IV. Different principles inform the disability legal system in each country, and consequently, there is a big difference in the number of

²⁶COUNCIL DIRECTIVE 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation.

incapacitations carried out in each country. In Spain, the number is clearly too high in comparison to the rest of the European countries.

- V.** Data for recent years points to a rise in the number of incapacitations, which seems contrary to the Convention's purpose. This, combined with the fact that many countries, as is the Spanish case, have taken more than a decade to adapt their legislation to the Convention, leads to the conclusion that the disability issue is not “essential” enough in the minds of government institutions.
- VI.** When discussing disability issues, we are talking about human rights, and there are, therefore, certain fundamental values that can never be denied or ignored. These include human dignity, a person’s right to decide about their own body, the right to social and political participation (which everway they choose to express it), and, of course, the fact that every human life has the same value.