



## **Papeles el tiempo de los derechos**

**“On the Right of Dependent People to the Promotion of Personal  
Autonomy and Care”**

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## 1. - On the right to autonomy in the context of situations of dependency

I do not believe that I should have to expend much effort in justifying the close relationship between questions of autonomy and independence and the discourse of human rights. Autonomy is the presupposition and foundation of rights; presupposition as it is associated with the very idea of the human being, foundation through its unity with the ideal of a dignified human life, which is the ultimate goal of human rights.

The discourse of human rights forms part of a conception of human beings in which autonomy is understood as one of their characteristics, a characteristic which is expressed in different ways and is conditioned by their social and personal situations. The achievement of a dignified life, understood as an aspiration to be achieved by gaining recognition of one's human rights, cannot be understood without the satisfaction and protection of autonomy. This is the point where independence connects with autonomy.

Independence constitutes an ideal which takes its meaning from the recognition and satisfaction of autonomy, indeed it is a kind of presupposition for it (real autonomy is achieved in a situation of independence), but it may be a consequence of it as well (the situations of dependency in a rights discourse presided by autonomy are solely and only those derived from an autonomous personal decision).

The very history of human rights can be described in terms of the struggle against dependence, or, if one prefers, the struggle for independence by human beings confronted with situations of power of different scales and origins. Evidence of this is

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constituted by the idea of rights as a limit on power, power understood not only in the political sense but also economically, socially and culturally and in the “natural” sense as well.

It can thus be seen that human rights try to protect autonomy, favor the exercise of independent acts and the disappearance of dependency not consented to. Autonomy and independence, to a greater or lesser extent, form part of the content of these rights.

However, it is also possible to construct an individual human right to autonomy of a general character. The recognition of such a general right to autonomy or independence must clear the obstacle of the confusion between the field of justification and that of legal technicality. Such a right must not be enunciated with such a high degree of indeterminacy and abstraction as to make practically impossible the guaranteeing or establishing of its essential content.

In general terms this right has two main elements: the element of non-intervention and the element of promotion. The former corresponds to what we might describe as the classic vision of autonomy and demands the largest possible degree of respect for autonomous choice. This corresponds to a situation of liberty (deemed in principle to be universal) and has as a corollary the non-right to interfere with that choice. This non-right, which can also be understood as an obligation not to act (negative obligation), is universally valid (that is, it affects both individuals and public authorities) and only lapses in specific and concrete situations (which must be determined in accordance with all the values present in the discourse of human rights).

The second element has to do with the individual’s capability of making a free choice, a capability which cannot effectively exist without the satisfying of certain necessities or without the possession of certain instruments and means. It corresponds to a legal situation (deemed in principle to be universal) and has as a corollary an obligation of promotion and provision. This obligation (which can be understood as a positive obligation, that is, an obligation to act), within a coherent rights discourse, should be universally valid and only lapse in specific and concrete situations in which the individual’s autonomy is affected in an unbearable manner. However, in our contemporary societies and in spite of the fact that it may appear contradictory, due to an exaltation of the value of autonomy (combined with the abandonment of analysis of the real situation of people and incoherent use of the idea and value of equality), this obligation has been projected solely and exclusively on public bodies.

In the foregoing logic is to be found the recognition of social cultural and economic rights as rights possessed by all human beings and also the rights of individuals and collectivities in specific situations (the rights of women, the child, of disabled people, of old people, etc...)

But together with these two phenomena, it is possible, from the same perspective, to consider the existence of an individualized right to autonomy which has as its corollary the general obligation to promotion and provision (if not universal in character at least in the ambit of the public authorities).

The identification of a right to autonomy in both of its elements demands the establishing of criteria which will allow it in itself to be distinguished from the content of it present in all rights, distinguished too from social, economic and cultural rights and, finally, distinguished from the rights of specific collectivities. These distinctions need to take into account, in concordance with the discourse of human rights, of the real situation in which the protection of autonomy is to be found and those contents of it in other rights that remain unsatisfied. Both of these aspects can be characterized as a lack of autonomy, or if one prefers, as dependence.

In general terms it is possible to state that the lack of autonomy, or dependency, has a social element. As is well known, it is this element which is defended in the field of disability, a posture which arises from the so-called social model and which may be possible to transfer to the area under consideration here. Many situations of dependency are produced by the manner in which services, environments and ways of life are socially organized. For this reason the study of dependency is, in the first place, a study which should be centered on the situation in which people find themselves.

However, this study would be unreal if, along with the focus on people's situations, it did not use another, which could be denominated as that of identity and which takes account of the physical and intellectual features and characteristics of the people concerned. This focus permits the integration of situations in which people find them and which derive from a wide variety of physical and intellectual factors. It is not a question of two independent focuses but rather of two that must be taken into account of at the same time. The identity and situational focuses are normally used in the justification and planning of anti-discrimination policies.

What the situational focus involves is an analysis of situations of dependency in which people find themselves. Starting from the situational focus, in principle it can be stated that the origin of the dependency is of no importance and that what is being

examined is the situation itself. Based on the degree of dependency involved, the type and level of aid that people need to reduce or eliminate their dependency can be determined. Starting from the identity focus, what is under examination is the origin of the situation of dependency. This origin could have social or individual (physical or intellectual) features or could be a combination of both. In view of all this, the main commitment would be to make social barriers to autonomy disappear and then establish the specific supports necessary to make the situation of dependency itself disappear.

As I have already said, in many cases the origin of a lack of autonomy is social in nature. The main route to making the absence of autonomy disappear would, therefore, be recognition of the universal right of access, understood both in physical and intellectual terms. The right to autonomy is intimately related with the right to universal accessibility but, as has occurred in the case of other rights, must not become confused with it.

In view of the foregoing, it is possible to establish a specific content for this right. This consists of care or support (physical or intellectual) in daily life (for the fundamental activities of daily life). Though I will later have to be more specific about what this actually means it can be said that it is the only element that might be left out of the content of the other fundamental rights. It is also worth emphasizing that the correct exercise of rights of those that form part of the general idea of “fundamental activity of daily life” may also require this support.

This right, generically speaking, seeks to protect those who find themselves in a situation of dependency by providing them with the assistance necessary for the development of the fundamental activities of daily life and for the correct exercise of their rights. There now emerge a series of questions that must be addressed. Firstly, who are the bearers of this right, secondly, what activities does it cover, thirdly, what set of obligations arises from it and fourthly, who are the subjects affected by these obligations.

In relation to the first of these questions it can be said that we are here dealing with a universal right, though it will only be exercised by those who find themselves in a situation of dependency that damages their development of a dignified human life. Given the imprecise nature of the concept and the fact that it depends on the person concerned and their environment, the putting into effect of this right must be done on the basis of a detailed analysis guided by both respect for and the desire to promote human rights. Given that this is a right that is unavoidably linked to the personal and

social situation of an individual and which generates a series of obligations in the form of provisions and services, a process must be devised for implementing it with a medical and psycho-social focus and which involves the intervention of the public authorities. This procedure cannot be limited to strictly personal aspects of the individual concerned but also to their immediate environment including, family, social and economic circumstances. The evaluation of these circumstances must never lead to a person being excluded from benefitting from the right but must rather have effect in the obligations arising from it.

The second of these questions refers to the meaning of what I have called the fundamental activities of daily life and for the exercise of human rights. In the analysis of dependency a distinction is normally made between basic and instrumental activities. The former term refers to self care and those activities necessary to live a normal life in one's home. These include dressing and undressing, eating, washing oneself, going to the toilet, going to bed and getting up from it, walking with or without a cane and spending the night alone. The second set of activities is more complex and involves a greater degree of personal autonomy. It relates to tasks which involve the taking of decisions and more complex interactions with the world. It includes such things as domestic chores, mobility and administration of the home and property. Regardless of this distinction, it is possible that people may disagree regarding what constitutes fundamental activities. As has already been mentioned, however, it is important to integrate into all these activities others also necessary for the exercise of fundamental rights. It is indeed the contribution to the development of a dignified human life that should be the decisive factor in deciding what constitute the fundamental activities of daily life.

In relation to the third question, it is possible to state that this right produces the need for compliance with a number of obligations which can be categorized into three types of provision: economic, assistential (personal and institutional) and health care. Obviously all these obligations ought to be complied with in a framework which combines the social and individual perspectives and be accompanied by a set of measures aimed at assuring their accessibility.

The economic provisions should be made in such a way to encourage the expansion of autonomy and, as far as possible, eliminate dependency. It is important to remember that this provision, though it may appear to be the most important in that it allows the person to construct their autonomous life plan, may involve a certain

abandonment of the commitment essential to this right if it is not accompanied by the rest of the provisions. Of particular importance is the combination of this provision with the assistential one. This latter has two dimensions. It is institutional in that it puts a set of assistential centers and a system of home care at the disposal of the dependent person, always subject to his or her autonomous decision. On the personal side there is the creation of a personal assistance service. This service should be involved in the fundamental activities of life and from an integral point of view it will affect matters of a physical as well as intellectual nature in the person's life. For this reason it should be fully professional and carried out in such a way as to promote autonomy. Finally, just like the rest of the provisions, the law ought to guarantee protection in the health field of both a general and specialized nature.

With regard to the fourth question, there can be no doubt that given that what is at stake is the right to a dignified human life it is the state which must guarantee this right either directly, through the development of an appropriate system or through a public or semi-public structure. The satisfaction of this right requires a set of investments on the part of the public authorities in order to guarantee access to the provisions and services as well as clear and precise determination regarding what they should consist of. Also, because it involves the development of a dignified human life and because it is a universal right, the obligations arising from it can be further held to bind all citizens (who, in any case, form the state), at least in terms of meeting the costs arising from the system or structure. And the same could be said about the person in a situation of dependency, always provided that the payment does not constitute an unbearable burden for them or interfere with or make impossible the achievement of independence.

## **2. - The right of dependent people to the promotion of personal autonomy and care in the Convention and the Law**

On the 13<sup>th</sup> and 14<sup>th</sup> of December 2006 two norms with great significance for questions relating to disability and dependency came into force. On the 13<sup>th</sup> of December 2006 the UN enacted the International Convention on the Rights of People with Disabilities and on the following day *Ley 39/2006 de Promoción de la Autonomía Personal y Atención a las Personas en Situación de Dependencia* (the promotion of

personal autonomy and care for dependent people law) came into effect in Spain. Both measures brought a right into existence related to that analyzed in the previous point.

The International Convention on the Rights of People with Disabilities is a normative text inspired, basically, by the social model and right from the outset (article 3), it reaffirms the value of autonomy, the liberty to take decisions and independence. In article 19, titled “The right to live independently and form part of the community”, it recognizes “The right of people with disabilities to live in equal conditions in the community”.

The right to live independently establishes measures aimed at the promotion of the autonomy of people with disability. This right, according to the Convention, implies the right to choose one’s place of residence on equal terms with other citizens (where to live, with whom to live, not subject to any particular system of life). It also implies access to general and specific services (among others, personalized home care).

The Convention prohibits discrimination motivated by disability and establishes, based on recognition of the universal dignity of all people, a strategy based on universal access combined with the development of those changes and supports necessary for the maximum protection and development of autonomy.

The Convention obliges the introduction of three fundamental changes in the treatment of disability. Firstly, a recognition that we are in the presence of a human rights discourse, secondly, that in order to meet the obligations arising from it requires rehabilitation, change and normalization in society and thirdly, a recognition that all people have the right to autonomy and independence regardless of whether they sometimes need help or support.

The right to live independently must be interpreted in the light of these changes. The right must protect, under the same conditions as all other people, the free choice - with the assistance that may be required - of where, with whom and how to live and of personal, home-based, institutional and health care. The bearer of the right must have access to the provisions and services which, freely decided by him or her, best strengthen his or her autonomy and social inclusion, in accordance with his or situation.

The *Ley 39/2006 de Promoción de la Autonomía Personal y Atención a las Personas en Situación de Dependencia* was presented as a great advance in the field of non-discrimination. The objectives of the law are clearly set out in its *Exposición de motivos* (explanation of motives) and its article 1.1. The former states that law is intended to “see to the necessities of those persons who, because they find

themselves in a situation of special vulnerability, require assistance to carry out the activities essential to daily life, achieve a greater degree of personal autonomy, and fully exercise their rights as citizens”, while the latter holds that the law seeks to “regulate the basic conditions which guarantee the exercise of the subjective right of citizenship, the promotion of personal autonomy and care of dependent people on the terms set down by law”, by the “creation of a System for Autonomy and Care of Dependent People”, and the guarantee “by the General Administration of the State of a minimum content of rights for all citizens throughout the territory of Spain.”.

### **3.- Some considerations on the configuration of law in the promotion of personal autonomy and care of dependent people**

It is possible to make some criticisms of *Ley 39/2006*, based on the content of the Convention. Perhaps the most important would concern its departure from the social model in the treatment of people with disabilities and dependent people. As well as the indeterminate character possessed by the new right in the law it is possible to make other criticisms which demonstrate its departure from what is expressed in the Convention. I have two points to make to support this statement. The first concerns the degree of dependence and the basic activities of daily life and the second has to do with the issue of personal care. These are two fundamental questions which concern the real exercise of the new right. There is a fundamental problem in the construction of the new law, it derives from its general focus which is not directed to promoting autonomy (but rather to protect dependent people) and deals with only certain situations while ignoring others of great importance (the most important of this is in the restrictions on economic provisions for leisure and culture but not for work and study) And I will not even mention the practical problems: the slowness of administration, the lack of resources, the absence of services, the poor training of evaluators, the regional inequality in the level of provisions, etc...

Article 26 of *Ley 39/2006* establishes three possible grades of dependency: Grade 1, moderate (“when the person needs help to carry out various activities of daily life, at least once a day, or the person has intermittent or limited needs for help to maintain their personal autonomy”), Grade 2, severe (“when the person needs help to carry out the basic activities of daily life two or three times a day but does not need a full-time carer or needs extensive support to maintain their personal autonomy”, and Grade 3, extreme dependency (“when the person needs help to carry out basic activities

of daily life several times a day and due to their complete loss of physical, mental, intellectual or sense autonomy needs the continual help of another person or needs generalized help for the maintenance of their personal autonomy”).

It can clearly be seen here that the degree of dependence is fundamentally determined by the capacity to carry out the so-called basic activities of daily life. These are defined by the law as “the person’s most elemental tasks which allow him or her to maintain a minimum of autonomy and independence, tasks such as personal care, basic domestic activities, essential mobility, recognize people or objects, orientate him or herself and understand and carry out simple tasks and orders”.

The definition of dependency offered here is excessively limited. It seems necessary to broaden it to include the exercise of those rights and those situations affected by mental and intellectual limitations (with the consequent extension of assistance and provision).

Also, when evaluating the degree of dependency the individual’s necessities in personal and social terms must be taken into account, a vision which is indeed established in the law that the standard for judging dependency would have among its reference points the International Classification of Functioning, Disability and Health (ICF) in order that disability be understood as the result of interaction between health and contextual factors.

The focus on the personal carer is also questionable. I have already underlined the importance of this figure in terms of the content of the right. Article 2 of the *Ley 39/2006* establishes that what is understood by the role of the personal carer is “service provided by a personal assistant who carries out or collaborates with the tasks of daily life of a dependent person with the aim of fomenting their independent life and promoting and strengthening their personal independence”. Article 19 regulates the economic provision for personal assistance, which according to the norm “has as its objective the promotion of the autonomy of extremely dependent people. Its objective is to contribute to the contraction of personal assistance during a number of hours which will give the beneficiary access to education and work as well as a more autonomous life in the exercise of basic daily activities (...).

Thus, while a correct appreciation of the role of personal care would hold that it should be directed it towards offering help to people to develop all types of activities that promote independent life the text of the law limits the activities of the carer to the home and the worlds of study and work while excluding such important matters as

leisure and free time. Furthermore, personal assistance could be extended to other areas such as the beneficiary's capacity to legally represent him or herself. The Convention, in effect, relies on a model of support that could be defined as being one of assistance. The will of the person with disability, in line with this principle, cannot be substituted but must rather be helped or assisted. And this is exactly where the role of the personal assistant becomes important.

There appears to be a necessity for the role of the personal assistant to be regulated. This would involve using an integral concept of what the role of the assistant (who carries out his or her role within a broad vision of what daily activities are) should be or, if necessary, various concepts of what that role should be depending on the exact sort of activity that is to be carried out.

Furthermore, according to the law, only people suffering from an extreme degree of dependency are to have access to this assistance with those suffering from severe or moderate dependency being excluded from it. My previous thoughts on the assessment of grades of dependency once more become relevant here. In any case, those classified by the law as being moderately or severely dependants are excluded from the possibility of receiving this assistance, even for work or education. These last two categories are only allowed to receive home help, something the law defines as “the set of activities carried out in the homes of dependent people with the objective of taking care of their necessities for daily life, provided by entities or companies accredited to do so: a) services related to the domestic necessities such as cleaning, cooking and others and b) services related to personal care in the carrying out the activities of daily life”.

Three final things need to be said about what needs to be done to make this right effective. The first is that all those working in this area need to be fully trained in a manner in accordance with the principles of the Convention, the bearers of the right should also receive such training. The second refers to the need to transmit the principles of the Convention throughout the education system, a move that will constitute a fundamental tool for the removal of social factors which cause or are present in situations of dependency. The third and final point refers to the necessity to modify the traditional perception of the individual factors which cause dependency. This perception is usually negative and it needs to be changed. It is necessary to adopt a positive outlook, an optimistic view of these factors and consider them as elements which enrich the diversity of society.