People with Disabilities, Self-Determination and Very Personal Acts

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The evolution of medical, social and economic sciences and, more generally, the way of thinking has profoundly changed the relationship between Society and people with disabilities: these persons, from the recipients of social protection and care, have become an active part of Society. Therefore, this publication analyzes the basis and limits of the powers of persons with disabilities in the context of ethical, political, religious and legal values.

Keywords: protection, incapacitated, fundamental rights, evolution of law, very personal acts, choices about health treatments.

Introduction

As it is known, the ONU Convention on the Rights of Persons with disabilities enforces “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” (Article 3). This Convention was implemented by the European Union, which approved it with a 2010 Council decision 2.


For its part, the Charter of Fundamental Rights of the European Union\(^3\) establishes, among other things, that “Human dignity is inviolable” (Article 1); that “The Union recognizes 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” (Article 26); and that “Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices” (Article 35).

The Italian Constitution recognizes the inviolable rights of man, both as an individual and in social formations (Article 2); it protects human dignity, guaranteeing the right to freedom (Article 13), the right to health and the right to refuse any medical treatment (Article 32).

The perception of disabilities and, therefore, the relationship between weak persons and protective institutions changed in the Italian Law too: the “amministrazione di sostegno” (also known as “a.d.s.”) was introduced in Italy by Law no. 6/2004\(^4\), due to protect “with the least possible limitation of the ability to act, people who are wholly or partly lacking autonomy in the performance of the functions of daily life, through temporary or permanent support interventions”. The legislation incorporates some solutions of the “Sauvegarde de Justice”, which represents one of the institutions for the protection of incapacitated subjects within the ambit of the French legal system. However, the influence of the Austrian “Sachwalterschaft” and the German “Betreuung” was really important.

The “amministrazione di sostegno” (which we can translate as “support administration”) represents a more modern and adequate measure compared to the traditional forms of incapacity already governed by the Italian civil code, i.e. “interdizione” and “inabilitazione”. In fact with the a.d.s. there is a more flexible model of protection of the person that is more respectful of his dignity. Aiming for the full realization of the human person in conditions of psychic or physical weakness, the leading purpose of the discipline of the a.d.s. is to promote the right of the person to express his will, if possible.

In the past, the law established the complete deprivation of the capacity for self-determination for people with mental disabilities; now, in the opposite sense, it provides for specific limitations on the capacity to implement legal acts. In fact, in the previous discipline, the weak person recipient of protection measures was precluded from fulfilling all or almost all the acts entrusted to the guardian. With the a.d.s. the beneficiary remains capable for all acts not prohibited by the judge.

### 1. Support administration (“a.d.s.”) and other institutions for the care of the weak person

The a.d.s. can be applied to people with mental illness, to people suffering from epileptic syndrome\(^5\), down syndrome\(^6\) and to severely depressed people\(^7\) – i.e. the elderly, drug addicts – as well as to per-

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sons only affected by physical incapacity if they are unable to provide for acts in their own interest. We have an administration of a “representative” type, which does not deprive the beneficiary of the capacity to perform a specific act which also the guardian has the power to do; besides that, there is also an “assistance” or “incapacitating” type of administration in which only the guardian – under the control of the Court – can perform the act on behalf of the weak person whom is instead non allowed to perform it autonomously.

“Interdizione” and “inabilitazione” are still in force but just as residual protection systems and must be ordered by the Court not depending on the severity of the disease but on the basis of the concrete needs of protection of the beneficiary. Basically, “interdizione” must be ordered only if the incapable requires a more radical exclusion from the legal acts or also to exclude the performance of some important acts that cannot be properly supervised by a.d.s. For example, “interdizione” can be ordered to safeguard the integrity of the personal assets which due to their importance cannot be administrated by the person with disabilities; moreover, it can be ordered if it is necessary to exclude fundamental freedoms such as marriage.

In force of Article 411 c.c., the judge can extend the effects of rules intended for “interdizione” and “inabilitazione” to the beneficiary of a.d.s.: among these, there are the prohibition of making a will, to make a donation or to acknowledge a child. According to some judges, also the prohibition of marriage or of “Unione civile” (between persons of the same sex) can be “extended” to the beneficiary of a.d.s. In these cases, where fundamental rights are somehow “restricted”, the technical assistance of a lawyer is necessary for the beneficiary. The right to sexuality can never be limited.

However, in the writer’s opinion, only with “interdizione” it’s possible to limit the right to marry. In fact the law declares the marriage (Article 119 c.c.) and the “Unione civile” (Article 1, co. 5, Law no. 76/2016) invalidity only with regard to the person declared “interdetto”, without references to the a.d.s. So the power given to the judge by Article 411 c.c. (to extend the effects provided for by the law for “interdetto”) does not allow the extension of the prohibition of marriage, contrary to what was held by the judges. The restriction of matrimonial freedom is exceptional. It should be remembered that the Charter of Fundamental Rights of the European Union recognizes the right to marry and the

11 See below.
right to found a family (Article 9). So only a Court formed by three judges\(^{20}\) can forbid the marriage\(^{21}\). Instead, every decision on a.d.s. is pronounced by only one judge.

2. Protection of incapacitated persons, very personal acts and fundamental rights

As it is known, the personality of the individual is evidently achieved also through the performance of negotiation or economic activity. There are then delicate regulatory areas, some of them recently emerged, such as choices regarding health treatments and other fundamental rights. So, since the beneficiary is not excluded from the legal activity, the a.d.s. discipline must be coordinated with the norms concerning the family, contracts, companies, trade, inheritance and donations.

The beneficiary suffers the limitation of his own capacity only with regard to those specific acts assessed by the judge as potentially prejudicial (for example contracts for great value goods).

In the Italian legal system, the guardian can only continue – but not start – the exercise of commercial enterprise on behalf of the “interdette”, and this both as an individual company and as a partnership. On the other hand the beneficiary of a.d.s. can directly start and perform business activities and participate in partnerships or capital companies if there are no specific restrictions ordered by the judge\(^{22}\). Sometimes, the beneficiary can be helped by the guardian\(^{23}\).

The balance between the opposing needs of autonomy and protection of the person becomes very complex with particular regard to the so called “very personal” rights and juridical acts; in the Italian Law these acts traditionally do not admit the participation of a legal or voluntary representative.

In the absence of prohibitions imposed by the judge, the beneficiary of a.d.s. remains fully capable of making wills and donations\(^{24}\). According to some authoritative opinions, the freedom to make a will only exceptionally can be limited, to respect the “human feeling”\(^{25}\). Moreover, the will is an act without prejudice to its author. The heirs, for their part, are protected by specific legal actions. They can contest the will if the author was non compositus when he made the act.

These considerations, together with some rules contained in the civil code (Articles 602, co. 1, 603, co. 2, c.c.), further confirm the inadmissibility of any replacement of the guardian in drawing up the testament. In fact that is called, by Italian law, “olograto” (“holograph”): it must be written only by the “hand” of testator and every participation of other person as well as the use of computer or mechanical systems cause the invalidity of the will (Article 602, co. 1, c.c.). The Article 603, co 2., c.c. – which discipline another type of will, made by a public official (a notary) – also prohibits the participation of a nuncius, who normally only reports the will of the testator.

\(^{20}\) In fact, the judgment of interdizione is given by a Court formed by three judges.

\(^{21}\) ANELLI, F. Il nuovo sistema delle misure di protezione delle persone prive di autonomia. Jus, 2005, p. 220 ss. V.


\(^{24}\) AULETTA, G. Capacità all’esercizio dell’impresa commerciale. In Enciclopedia del diritto, VI. Milano: Giuffrè, 1960, p. 79.

\(^{25}\) BONILINI, G., 2018, p. 433 s.
However, with a singular (and illegitimate) decision, a judge has appointed a special curator of weak person (affected by amyotrophic lateral sclerosis) to transfuse, in a holograph will, the last wishes of the beneficiary, expressed through an ocular pointing communicator. This is an illegitimate decision, even because it allowed the participation of another person in the drafting of a holograph will. The provisions of the law (on holographic will) are clearly violated and the decision of the judge of a.d.s. cannot make valid a will contrary to the same law.

The legitimacy of the intervention of the legal guardian in the fulfillment of donations is also very doubtful. In one case, a judge has authorized the guardian to proceed, in the name and on behalf of the beneficiary, to the donation of a house, after verifying the intent of the beneficiary and the absence of damage for him. In another case, the guardian has been authorized by the judge to donate to the daughters of the weak person, in the name and on behalf of the same incapacitated, the co-ownership of a real estate property. This appears patently illegitimate: the civil code excludes the possibility of making donation for those who haven’t full capacity to dispose of their assets. It must be remembered that the Article 1 of the Protocol to the Convention for the Protection of Human Rights and Fundamental Freedoms establishes that “Every natural or legal person is entitled to the peaceful enjoyment of his possessions. No one shall be deprived of his possessions except in the public interest and subject to the conditions provided for by law and by the general principles of international law”.

The hazards of these kinds of acts are evident if we consider, for example, the case of a request proposed by a support administrator who was also the brother of a weak person: he asked that the person with disability was authorized by judge to draft a will, with the same brother as beneficiary. In this case, the Court rejected the request; according to judge, the person who was supposed to make the will was non compositus mentis and neither was ascertainable his volition.

The beneficiary can freely marry, unless there are limitations.

According to some judicial decisions, the spouse beneficiary of “interdizione” may request the separation or dissolution of the marriage through the legal guardian and with the authorization of the tutelary judge; this possibility is admitted due to protect the incapacitated spouse from violations of marriage obligations committed by the partner.

It is not excluded that the same principle could be also extended to the “a.d.s.”; nevertheless, in the writer opinion, such personal decisions should be expressed only by the beneficiary, if able to assume them, with the exclusion of any intervention by the legal guardian.

In these cases, the best way to safeguard the interests of the weak person could be the proposition, by the legal representative, of a request for compensation or the proposition of the so-called exceptio doli, which allows the rejection of the claims based on the abuse of the right; in some circumstances,
that appears to be more appropriate than acting with the request of separation or divorce. In the same way, only the part of the “Unione civile” can ask for its dissolution, according to the Article 1, co. 24, of Law no. 40/2016, with no possibility for the support administrator to perform that very personal act.

The Law no. 6/2004 does not contain specific provisions regarding non-pecuniary acts but only provides that the choice of the guardian must be made with exclusive regard to the care and interests of the beneficiary; the same Law requires the guardian to consider needs and aspiration of the beneficiary.

Many judges, however, had recognized to the legal guardian the power-duty to express consent to any medical treatment for the beneficiary: otherwise, the recipients of the measures of protection could not exercise very personal rights. This conclusion is certainly correct and complies with the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine. The Article 6, co. 3, establishes that “where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law”.

In a very well-known case in Italy, a person was in a permanent neurovegetative state and could not express any consent on artificial feeding therapies: however, the guardian requested authorization, in the name and on behalf of the beneficiary, to refuse such therapies. The Supreme Court, as it is known, has affirmed that the very personal right to health, by its nature, does not allow the guardian to dispose of it on the behalf of the individual in a state of total and permanent unconsciousness. So, it is necessary to reconstruct the presumed will of the unconscious patient, taking into account the desires he expressed before the loss of conscience, or inferring that will from his personality, his lifestyle, his inclinations, his reference values and his ethical, religious, cultural and philosophical convictions.

Recently, the Italian legislator introduced rules to protect the freedom of choice of medical care. According to the Article 3 of Law no. 219/2017, if a guardian has been appointed, the consent to treatment is expressed or refused by the same guardian, taking into account the will of the beneficiary in relation to his ability to understand. If there are no choices previously declared by the beneficiary when he was of sound mind, in case of disagreement between the legal guardian and the doctor about proposed care, the decision is left to the judge.

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40 See also below.
However, the Constitutional Court has ruled out that power of representation for health choices always involves power to refuse the medical treatment necessary for the maintenance of life\(^{41}\). The judge must specifically evaluate the clinical conditions of the protected person and the power to refuse treatment must be specifically attributed to the guardian.

It must be emphasized that life-saving treatment can never be rejected – not even by the judge – if the beneficiary has not expressed, when he was of sound mind, the refusal of the same care, according to the provisions of Article 1, co. 4 and 5, and of Article 4 of Law no. 219/2017. The Article 1, co. 4 of the same Law establishes that the consent or the refusal to the therapies must be expressed in written form or through video recordings or, for the person with disabilities, through devices that allow them to communicate. According to the Article 4, in view of a possible future incapacity to self-determine and after an adequate information any adult person who is of sound mind may express authenticated private writings or public deeds in relation to (future) health treatments, including its refusal. The right to refuse medical treatment is very personal\(^{42}\) and can only be exercised by its owner, in the forms prescribed by law. The representative can only report the will of others but cannot form it, neither directly or indirectly by its reconstruction.

For these reasons, it is clearly wrong the very recent pronouncement\(^{43}\) of a judge who “omitted” to take any decision about the support administrator (possible) authorization to order the suspension of a therapy; according to the judge, the support administrator is fully entitled to refuse and to propose treatments once he himself had ascertained the will of the administered person in reference to the health treatment in question (and this also presumptively, in the light of the declarations made in presence of the same administrator).

**Conclusions**

The freedom of the person is at the same time the purpose and the limit of his/her dignity protection.

The individual subjected to a.d.s. can directly perform very personal acts, even those with patrimonial content, if in a position to decide with full lucidity; otherwise, those acts can never be executed by the guardian, even if he only integrate the will of the beneficiary. In this context, the beneficiary of the protection is the only person who can the refuse medical therapies which are necessary for the survival (with the exception of so-called “therapeutic obstinacy); this decision cannot be left to the guardian.

The same principle can apply to other fundamental choices, such as separation and dissolution of the marriage.

Self-determination is essential; that said, “substitution” in personal choices should be considered as exceptional and seen as a “extrema ratio”.

Opposing solutions do not grant autonomy but on the contrary endanger – maybe erase – fundamental rights of weak persons.

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Legal practice
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Summary

The evolution of medical, social and economic sciences and, more generally, the way of thinking has profoundly changed the relationship between Society and people with disabilities: these persons, from recipients of social protection and care, have become an active part of Society. Their full and effective participation is assured on an equal basis with others. Consequently, to promote their full integration, international and European laws have recognized the right to their
self-determination. As a result, a new balance must be found between the aspirations to decide of the weak person and the support provided for by the law. Therefore, this publication analyzes the basis and limits of the powers of persons with disabilities in the context of ethical, political, religious and legal values.

Neįgalūs žmonės, savarankiškas apsisprendimas ir išimtinai asmeninio pobūdžio veiksmai

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Santrauka
Medicinos, socialinių ir ekonominių mokslų raida, apskritai pati mąstysena iš esmės pakeitė visuomenės ir neįgalių žmonių santykius. Socialinės paramos išlaikomi asmenys tapo aktyvia visuomenės dalimi, jų visiškas ir veiksmingas dalyvavimas visuomenėje užtikrinamas lygiais pagrindais su kitais asmenimis. Siekiant skatinti visapusišką neįgalių integraciją, tarptautiniai ir Europos teisės aktai pripažino žmonių, turinčių negalią, teisę į savarankišką apsisprendimą. Tai lėmė poreikį rasti neįgaliesiems teikiamos įstatymu garantuojamos socialinės paramos ir siekio savarankiškai apsispręsti pusiausvyrą. Atsižvelgiant į tai, šioje publikacijoje etinių, politinių, religinių ir teisinių vertybių kontekste analizuojama problematika, susijusi su neįgaliau teisių įgyvendinimo pagrindais ir ribomis.