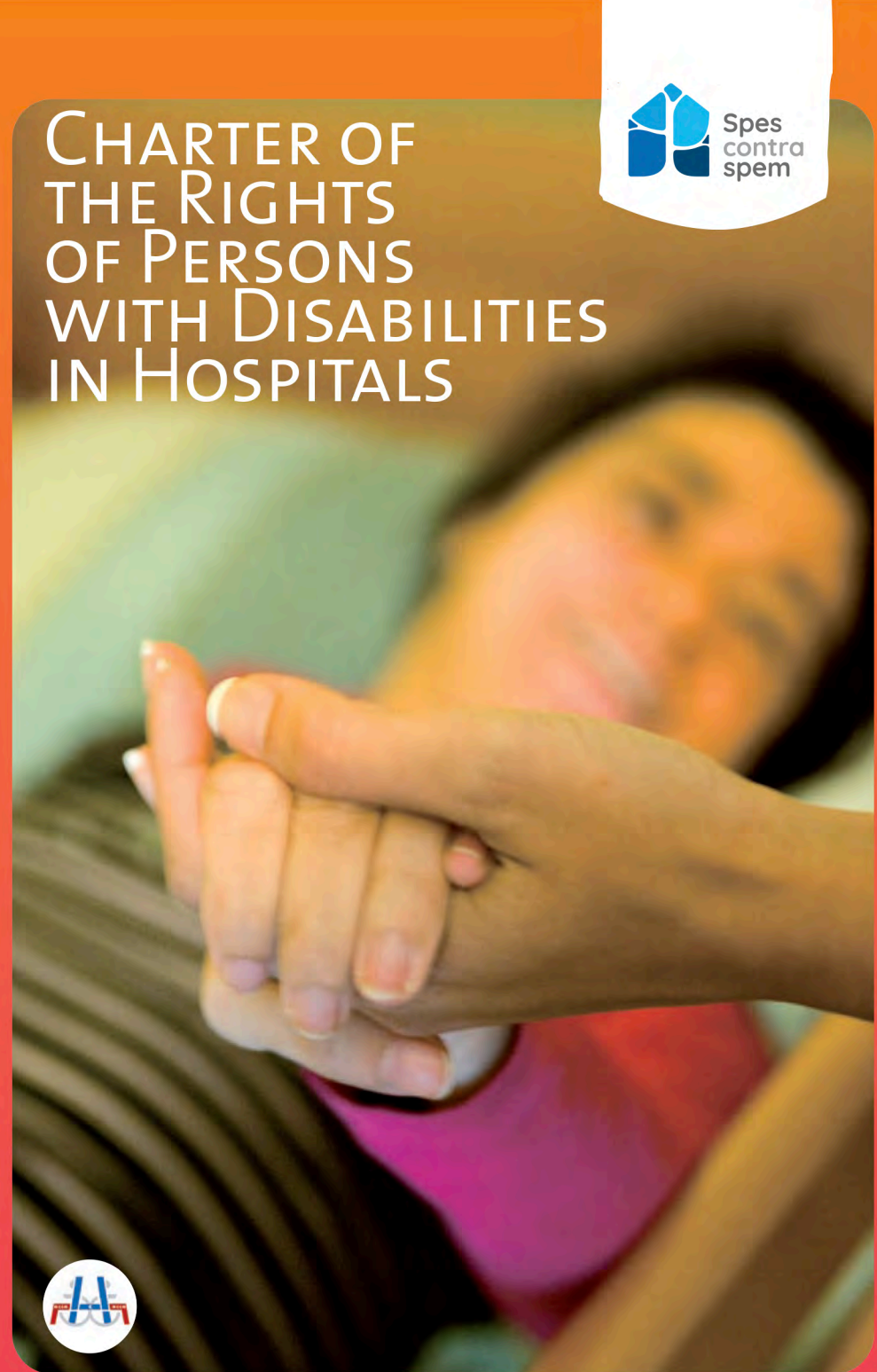




CHARTER OF THE RIGHTS OF PERSONS WITH DISABILITIES IN HOSPITALS



They have joined

A grid of logos for various Italian disability organizations, including:

- ABC - associazione bambini cerebrali - federazione italiana
- Associazione Disabili Visivi ONLUS
- AGCI solidarietà - ASSOCIAZIONE DI SETTORE DELLE COOPERATIVE SOCIALI
- AGSA 14710 ONLUS
- ASSOCIAZIONE Habitat per l'Autismo onlus
- AISWIH
- ASSOCIAZIONE ITALIANA PERSONE DOWN
- Associazione Italiana Sindrome 'X-Fragile'
- Casa di Pirale
- Duchenne Parent Project
- IL DM
- Famiglie SMA
- fantasia
- FISH - federazione italiana per il superamento dell'handicap
- IL BRUTTO ANATROCCOLO Cooperativa Sociale
- TRIBUNALE DELLA SALUTE SEZIONE DI BOLOGNA
- U.F.H.A. - ONLUS Unione Famiglie Handicappati
- Viaggiare per un Sogno: oltre le barriere
- L'IDEA PRISMA 82
- Mitocon



CHARTER OF THE RIGHTS OF PERSONS WITH DISABILITIES IN HOSPITALS



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This work stems from an actual experience.

Time and again, a particular event leads us to draw general conclusions. Personal experiences provide an opportunity to develop abstract considerations, to generalise, and subsequently -by reversing the process - to transform once again abstractions into concrete responses. **This story starts from our encounter with Tiziana, and what befell her in a hospital in Rome.**

Tiziana was a woman with serious disabilities, who lived in a household for persons with severe handicaps. Her comprehension capability was greatly impaired, and even more so her ability to express herself. Even so, those who throughout the years had patiently learned to decipher her plain but meaningful language had come to love her, since the mechanism of love between two persons is always the same: they first start to know each other, and then to value the other for all that he or she is and is not. And this is how it has been for many years with Tiziana in *Casablu*, the household which took her in.

Helping her to eat required a lot of patience, and to make her swallow a pill one had to talk and try to convince her, while she stubbornly kept on refusing it. It was a daily, playful skirmish, which eventually ended with an embrace, laughs and the pungent remarks Tiziana addressed to everyone. This was why she was

loved: she always found a word for defining years of relationship –indeed, a unique ability to synthesize. One day in November, Tiziana fell ill - a simple flu - but her health being frail it was decided to hospitalise her. Unfortunately, the strict rules governing hospital life allowed the persons who for years had constantly taken care of her to see her only during “visiting hours”. The rest of the time Tiziana must stay alone. Hence, the distress of being ill and left alone was worsened by all the problems of a person who does not communicate “normally” and does not have “normal” needs. This made it difficult for nurses to administer treatment, or understand her when each morning she tried to tell them she was cold when windows were left open.

Indeed, an attentive perception of patients’ needs is essential for determining their treatment. Consequently, Tiziana developed pneumonia, and on December 12, 2004 she died, unheeded and alone.

Since then, several years went by: the necessary period for turning this work from a protest - or the “reparation” of a wrong - into an attempt at transforming a tragic story into a hope and a commitment for the benefit of many other persons like Tiziana.

This is the vision which has been guiding us for over two decades, and ***Spes Contra Spem*** (hope against all hopes) was the name given to the Association which founded and still runs *Casablu*, since **hope** is the force that overcomes all difficulties, that looks far ahead, that builds...

Tiziana's story taught us how difficult daily life in a hospital can be for a person with disabilities. A long wait in the Emergency room, undergoing invasive exams, hospitalisation - these are all experiences which each one of us can live through with more or less distress. For persons with disabilities, though, they can be devastating. The feeling of being locked in a room with other persons who suffer, or moan, or even scream, could be intolerable for a person with a behavioural disability. To be in a hospital, having undergone even a simple surgical operation, and to be unable to communicate one's physiological needs - having been deprived of the continuous presence of someone capable of perceiving them - can have a very serious impact on an already frail patient.

We referred to a concrete case - the story of a person we loved - in order to explain why we developed a project which has the ambitious objective of helping the health system to provide adequate responses, convinced as we are that this is an ethical and human obligation.

True, the instruments to be deployed require financial resources, but above all they ask for a profound and far ranging cultural change to be achieved through a strong commitment towards training and leading health professionals to become fully aware of this critical issue. Consequently, the present *Charter* has been formulated so that the proclamation of each single right be followed by an explanation, and above all by an example as to which instruments are required to allow the exercise and enjoyment of this right by each single person with a specific disability - be it an intellectual, relational, sensorial, or mobility impairment.

Actually, a major problem when treating persons with disabilities is a certain attitude by health professionals of considering any treatment provided to these patients - and therefore any diagnostic path - basically useless. This approach does not necessarily derive from a bias; at times, it arises from the conviction that any care would surely cause a further, useless suffering to that person. In many cases, however, the conviction that disability and illness coincide is unfounded. This problem is aggravated by the fact that the administration of any diagnostic and/or therapeutic act, even a relatively simple one, can actually turn out to be very complex - for example, the taking of a blood sample, an x-ray of the chest, or a cutaneous suture in a patient with serious cognitive deficit associated with behavioural problems, or in a patient with a spastic tetraparesis. Moreover, co-morbid conditions typically associated with certain disabilities (e.g. epilepsy, neurological bladder), as well as complex pharmacological therapies, lack of autonomy and the consequent need for constant care and attention, as well as communication difficulties, cause these patients to become extremely frail - thus heightening the risks always inherent in all diagnostic and especially surgical procedures.

Problems arising during hospitalisation can likewise be quite complex. When a complication arises, it can be difficult for persons with disabilities, or for their caregivers, to find a referral specialist. On the other hand, primary care practitioners tend to delegate to the specialist who is in charge of the patient the identification and solution of all medical problems not directly connected with the pathology responsible for the

disability. Unfortunately, at present the assignment of these persons to the care of a medical professional is still too often taxing, while care managers are still very few. Holding training courses for health operators on disabilities and related problems is consequently a primary need. Persons with disabilities have the right to access to all cares, not only those connected with their possible specific pathology, but also those which are necessary for other general or special pathologies. Moreover, prevention programmes should be envisaged, with clinical, laboratory, and instrumental prevention screenings (i.e. dental, gynaecological, dermatological, and other screenings). However, the difficulty of performing even simple diagnostic or therapeutic manoeuvres, the complexity of pathologies and of health services management, together with the difficulty of establishing a relation with patients with disabilities, all enhance the risk for many medical problems to be disregarded or totally neglected.

In this field a fundamental document is the *UN Convention on the Rights of Persons with Disabilities*, adopted by Italy through Law 18/2009, which in Article 25 establishes the right to health services and the obligation for health professionals to “provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons.”

It also holds true that the right to health services, like all other human rights, is based on the intrinsic dignity of each human being. A dignity characterised by universality (it pertains to all individuals) and by

innateness (it is ingrained in human nature, and is not affected by any change in health conditions, or by the loss of functions and abilities). The present work evidences how the rights set out in Article 25 of the UN Convention can find a concrete implementation through the *European Charter of Patients' Rights*, as applied to this specific class of patients.

One of the key principles of the above mentioned UN Convention is the “*reasonable adaptation*” principle, which sets out that all necessary and appropriate modifications and adaptations - that do not impose a disproportionate or excessive burden - be implemented in order to guarantee to persons with disabilities the enjoyment and exercise of all human rights.

The expression “disproportionate burden” does not refer only to the financial aspect, but also to the fact that the means exploited should be commensurate to the goal being pursued; and health structures should take into account this principle when implementing the rights embodied in the *Charter*.

Our hope is that the present *Charter* may constitute the first step towards the application in health structures and in hospitals of diagnostic and therapeutic paths tailored to persons with disabilities. This approach is already being employed in some isolated cases², which can promote a diverse view on this issue within health structures.

We endorse the following statement by A. Pessina: “*Persons with disabilities do not have special needs... they have the same needs as all empirical subjectivities, as they are not special persons, but human beings affected by certain limitations.*”³

¹ *UN Convention on the Rights of Persons with Disabilities*, approved on December 13, 2006, and ratified by Italy through Law 18 of March 3, 2009.

² Project DAMA (disabled advanced medical assistance) of the San Paolo Hospital in Milan, introduced in the year 2000.

³ Pessina A. *Barriere della mente e barriere del corpo. Annotazioni per un'etica della soggettività empirica*, in *Paradoxa, Etica della condizione umana*, Milano, Vita e Pensiero, 2010.

SPES CONTRA SPEM

The social cooperative *Spes Contra Spem* was established in Rome in 1991. Its name, “hope against all hopes” describes its characteristics: a group of persons who tenaciously and committedly devote themselves to the realisation of a project.

With this ‘vision’ in our hearts and minds, the dream of setting up a household for persons with disabilities, where they could live serenely in a friendly and cosy milieu, started to take form.

Today, *Spes Contra Spem* runs four households in Rome for persons with disabilities, youths at risk, and young disturbed adults who live an experience of autonomy. The aim is that of protecting and taking care of these persons by meeting their needs - from youth disorders, to the difficulties of persons with disabilities, up to social emargination issues.

THE HEH PROJECT

The **HeH Project** originates from the actual experience of the difficulties with which persons with disabilities and caregivers are confronted when hospitalisation is required. Accordingly, the need to undertake actions aimed at favouring a hospitalisation purposely tailored to persons with disabilities was strongly felt. A project was then launched, whose first objective was the proclamation of the rights of persons with disabilities in hospitals; i.e. the same rights envisaged for all patients which, in order to be fully enjoyed by persons with disabilities, ask for particular procedures and instruments: procedures and instruments that health structures shall make available. To this end, a group of persons with different qualifications met on a monthly basis to open a discussion and formulate the **Charter of the Rights of Persons with Disabilities in Hospitals**, based on the *European Charter of Patients' Rights*. The drawing up of the Charter was entrusted to a qualified Scientific Committee, and was endorsed by numerous associations of persons with disabilities.

The project contemplates various stages:

- **The presentation of the Charter** to the health sector, to associations, to the social cooperation area, to the political and administrative governance of the national and regional health systems, and to public opinion. It has already been submitted to various hospitals in several Italian cities, as Rome, Milan, Lecce, Siena, Legnago, AUSL Alto Vicentino, and others.
- **The training of health service providers.** Another primary objective of the project is the eradication of cultural barriers, often simply arising from a limited knowledge of this reality by physicians and nurses. To this end, the project provides for the organisation of training courses, masters, and meetings, in cooperation with university institutions and professional associations.
- **The creation, within hospitals, of health paths focused on persons with disabilities**, also profiting from the positive experiences already existing on the national territory.



ARTICLE 1 Right to Preventive Measures

Every individual has the right to a proper service in order to prevent diseases.

“ Persons with disabilities shall be provided access to all general medicine services and to screenings normally provided for general population. In particular, general medicine, in connection with the territorial network of health services, shall undertake to meet all non strictly specialist needs. Also persons with disabilities must be given the opportunity of acceding to the screening programmes related to various pathologies, established for the other patients of the same age and sex.

”

example

For persons with multiple disability, serious intellectual disability, or suffering from autistic spectrum disorders, the distress of these screenings must be weighed against the risks and benefits they involve, in agreement with patients or with their legal guardians.⁴

⁴ The term “guardian” refers to both a legal guardian, and a surrogate decision-maker. The problem remains as to the numerous adults with intellectual disability who, though unable to take autonomous decisions, do not formally have a legal representative. While in a state of necessity - which compels the medical personnel to act in the best interest of the patient - there is no problem, it does emerge when faced with diagnostic and therapeutic options that are both potentially valid.

ARTICLE 2 Right of Access

Every individual has the right of access to the health services that his or her health conditions require. Health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services.

Persons with disabilities shall not be denied the access to a service, or a clinical path owing to the type or seriousness of their disability. The right of access to services of a person with disabilities is often precluded both by the presence of architectural barriers in health structures, and of cultural barriers in health operators.

The services repayment systems should take into account the clinical complexity which often these patients present, and which involves higher costs; indeed, also relatively simple procedures and operations impose a particular organisational burden in terms of means and staff. This might deter health structures from providing services and hospitalising these patients, thus engendering a further economic discrimination.

example

Persons with a severe intellectual disability, or suffering from autistic spectrum disorders might have problems when staying in the waiting rooms of health structures, especially in the Emergency area. This is why they must be granted a preferential lane.

Tactile paths must be arranged for partially-sighted persons, together with a map of the place in Braille (elevators).

Alternative systems (e.g. luminous displays) instead of vocal calls should be envisaged for deaf persons.





ARTICLE 3 Right of Information

Every individual has the right of access to all kind of information regarding their state of health, the health services and how to use them, and all that scientific research and technological innovation makes available.



Patients with disabilities have the right to receive information and continuous, accurate, and understandable updating on their conditions, where necessary, through augmentative/alternative communication modalities, including the *Italian* sign language and the recourse to images. They also have the right to accede, at any time, to their clinical file, and to raise questions and receive clear and precise answers. Should the patient's disability not allow to comprehend, and/or interact with, the health professionals - even through appropriate communication modalities - that patient's guardian shall be provided information and be given access to any useful or requested information. In particular with reference to progressive disabilities, physicians and patients should discuss beforehand a treatment plan (advanced care planning) which establishes for each stage of the disability the agreed diagnostic and therapeutic procedures to be enacted.

example

It is necessary to try and communicate with patients in a way which is adequate to their cognitive level, without ever ignoring their presence. Health professionals should adopt specific postural approaches and place themselves in front of patients and at eye level: for example, to get seated in front of a patient in a wheelchair. Physicians shall seek to utilise the communication aids employed by the person with disabilities (for example, image cards, transparent charts, magnified fonts, Braille).



ARTICLE 4 Right to Consent

Every individual has the right of access to all information that might enable him or her to actively participate in the decisions regarding his or her health; this information is a prerequisite for any procedure and treatment, including the participation in scientific research.

A consensus to a diagnostic or operative procedure is the result of a shared decision, built through the relation established between physician and patient. The granting of the consensus is the last act of the patient's information process. The signing of a form does not exempt the physician from the obligation to provide information in a simple, clear and understandable way, nor from the personalisation of this communication. Throughout the period of treatment, it is of fundamental importance for the physician to be ready to have one or several conversations with the patient and his or her guardian, and to provide them with a psychological support.

The above evidently applies also to patients with disabilities. Should they be unable to understand - even through a simplified language or suitable communication modalities - the guardian shall be involved. Every patient should be **timely** provided with all information regarding his/her health conditions, in order to take decisions as to treatments and/or surgery. The same applies to persons with disabilities and, where their disability or pathology might complicate the therapeutic choice, they have the right to be informed in due advance.

Health professionals (physicians and nurses) have the duty to provide explanations whenever requested, and to express them in the clearest possible way. Should the guardian take over, he/she must be involved in all decisions.

Indeed, patients have the right to be informed on their health conditions, but they also have the right to decide not to be provided with that information or with any guidance by health professionals.



example

For deaf persons who communicate through spoken language, it might suffice to speak slowly facing the patient. For partly deaf persons who communicate through sign language, it will be necessary to provide for interpretation in the *Italian* sign language.





ARTICLE 5 Right to Free Choice

Each individual has the right to freely choose from among different procedures and providers of health services, on the basis of adequate information.

In the absence of a proven incapability, persons with disabilities have the right to express their will regarding the procedures and providers of health services. This clearly implies the planning of instruments capable of allowing any person to exercise this right, including the support which might be required in the exercise of his or her legal capacity, in accordance with Article 12 of the *UN Convention on the Rights of Persons with Disabilities* (equal entitlement before the law). Under all circumstances, it shall be necessary to establish a model of physician-patient relationship based on shared decision-making.

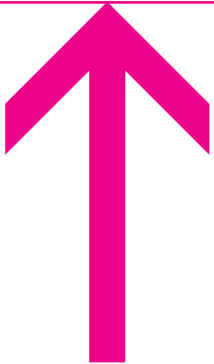
example

Medical professionals shall help patients with sensorial disability to understand all information which, under this right, must be provided to them, by utilising any appropriate aid (Braille system of writing for partially-sighted persons, sign language for deaf patients). In case of a proven incapability of patients to take decisions - even with an appropriate support to the exercise of their legal capacity, as in the case of a severe intellectual disability - the guardian shall have the right to choose the diagnostic path, or the therapeutic procedure, which must always guarantee the best possible solution for these patients. Physicians should in all cases provide the legal guardian with all information on the different procedures and treatments, in the presence of the patient. Should a problem arise, because of a disagreement between the guardian's choice and the indications of the health professionals, the advice of the Ethical Committee of the structure and/or a clinical bioethics advice shall be requested.

ARTICLE 6 Right to Privacy and Confidentiality

Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist examinations, and medical or surgical treatments in general.

All data and information regarding the health conditions, therapies, and surgical treatments are considered sensitive data; they therefore need to be adequately protected. Patients have the right to choose to whom their sensitive data may be communicated.



example

Physicians will have to choose an appropriate place where to deal with those issues, making sure that the presence of those attending is strictly necessary. A patient with paraplegia, who is on a wheelchair, shall not be provided information in the corridor, or in a public milieu; the physician shall seek an appropriate space where he or she can sit in front of the patient.





ARTICLE 7 Right to Respect of Patients' Time

Each individual has the right to receive necessary treatment in a short and predetermined period of time. This right applies to each stage of the treatment.



There is a difference between performance times - which must be particularly rapid, in case of pathologies that can lead to further complications - and the communication and processing times, which for patients with disabilities might require a slowing down compared to the standards of other patients. The health performances shall be timely and shall respect the times of the person with disability and of his or her family.

Health services shall establish the waiting times within which certain performances must be provided, on the basis of specific standards and of the urgency of the case. The appropriate structures shall guarantee to each individual the access to services, by ensuring his/her immediate entry in the waiting lists, if envisaged. All physicians shall devote an adequate time to their patients, including the necessary time for providing information.

example

Patients with cognitive disabilities have the right to utilize the Emergency lane, thus avoiding the stress and discomforts which the hospital milieu entails. All physicians shall respect the times of patients - as regards both expression, and understanding - remaining at their disposal as long as needed.

The simple taking of a blood sample in a person with autistic spectrum disorders - who might experience it as an aggression - can require quite a long time. It is thus necessary to set aside an appropriate space; not to be in a hurry (*Oh my God, persons waiting are becoming a crowd!*); and to try and explain, together with caregivers, the procedure so that patients may consider it "more familiar".

ARTICLE 8 Right to the Observance of Quality Standards

Each individual has the right of access to high quality health services, on the basis of the specification and observance of precise standards.

The right to high quality health services requires that health structures and professionals perform satisfactory levels of technical treatment, comfort, and human relations. This implies the specification and observance of precise quality standards set out through a procedure of public consultation, which are periodically reviewed and assessed, through monitoring, audit and inspection mechanisms.

A periodical review of the quality of treatments provided by the structure to persons with disabilities could be suggested; for example, this scrutiny could be carried out by a Committee made up also by representatives of the associations involved. Moreover, as done for hospitals that are mindful of the needs of women and are signalled by a pink stamp, a similar indication could be adopted for hospitals particularly attentive to the needs and care of persons with disabilities.

Persons with disabilities have the right to obtain a diagnosis of those pathologies which can co-exist with, and supervene, in their conditions. They further have the right to all treatments not only those connected to their specific pathology, but also those which are needed for other specialist pathologies. Furthermore, specific programmes should be formulated, which involve clinical, laboratory and instrumental preventive screenings (dental, gynaecological, dermatological, and other screenings). All this must be complemented by essential treatment levels.

Disability must not be considered as a limitation for the enjoyment of this right. Regardless of their disability, sex, ethnical origin or religion, all patients are entitled to accede to high quality treatments and services. No physician or health structure can consider a patient less worthy than another.

Ever so often, when persons with multiple or medium-to-serious intellectual disabilities need high technological content diagnostic and therapeutic procedures - which are limited or expensive - physicians tend to deem these procedures inappropriate, not pursuant to a clinical assessment on the appropriateness of the intervention, but because of a cultural prejudice: i.e. to use these devices for a person with disabilities could mean to deny a patient with no disabilities their use.

example

In medical sectors with high technological contents, or scarce resources, the risk of discriminating persons with disabilities does exist.

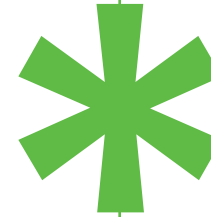
This occurs when, for example, a child with a Down syndrome is denied a heart transplant, because of a serious intellectual disability, or because it is deemed that anyway a transplant would not mend his "sad" condition.

Or when it is prejudicially decided not to administer to a patient with multiple disabilities an exacting though life-saving therapy, as chemotherapy, without having previously assessed its risks and benefits.



ARTICLE 9 Right to Safety

Each individual has the right to be free from harm caused by the malfunctioning of health services, medical malpractice and errors, and has the right of access to health services and treatments that meet high safety standards.



Safety must start from the structure where persons go to receive adequate treatment. The path to reach the assigned ward must not place patients in danger. In their approach health providers should avoid the emergence of any undesired emotional state. The prescribed and administered therapy must be compatible with stated impairments, disabilities, or handicaps.

The absence of dangers for persons with an impairment, disability or handicap would make it more difficult for harmful events and accidents to occur - which means a better quality of life. And not only the environment, but also the therapy must be safe.

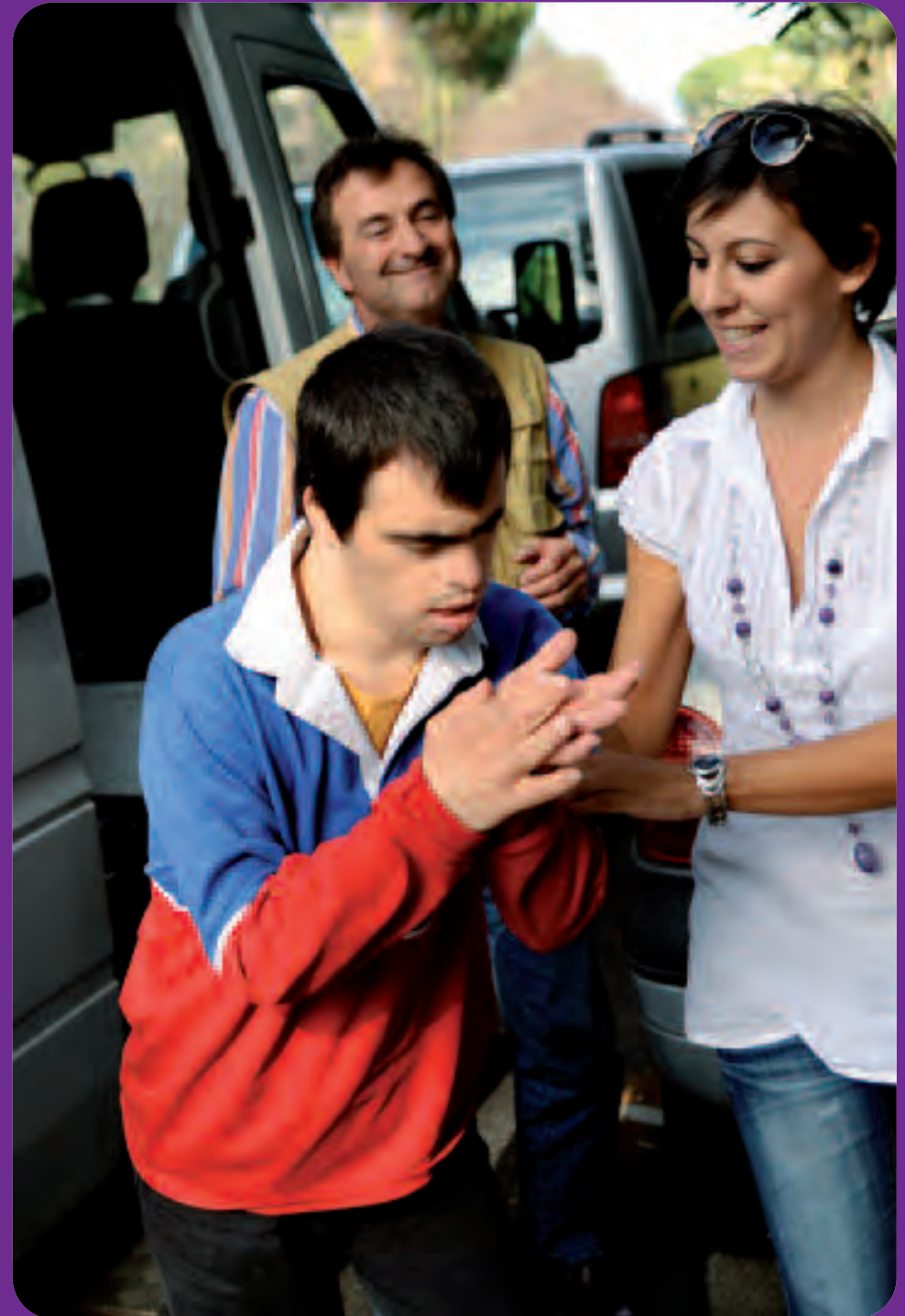
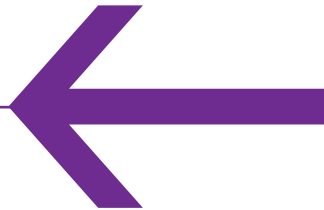
example

Access to hospitals must be guaranteed precluding any dangerous situation. Blind persons, for example, should be able to reach the service they are heading towards by following a tactile path expressly arranged with explicative boards in Braille. For patients with psychic disorders it is necessary to assess their willingness to be examined, as well as the type of interpersonal contact they tend to establish with the examining physician, which is often altered. It is therefore extremely important to distinguish the basic characteristics of persons with disabilities from what might be caused by the concurrent presence of other psycho-pathological problems. This clearly involves a good knowledge of the patient. This is why the assessment of his or her psycho-pathologic conditions in a hospital setting - deeply different from the habitual milieu where the patient lives - is a complex process, which risks falsification, and positive or negative fakes. A means for reducing this risk is to wait for patients to get acquainted with the new context, and also to gather as much information as possible on them, basing this appraisal also on the documents at hand and the persons accompanying the patient.

ARTICLE 10 Right to innovation

Each individual has the right of access to innovative procedures, including diagnostic procedures, according to international standards and independently of economic or financial considerations.

Persons with disabilities must be involved in technological and cultural evolution, by actively participating in the process. These persons' specific conditions shall have no impact on the choice to take part, or not, to experiments. The design of new instruments and appliances must be developed and realised so as to be utilised also by persons with disabilities.





ARTICLE 11

Right to Avoid Unnecessary Suffering and Pain

Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness.



Health professionals should constantly be aware that persons with disabilities feel pain or suffering just as any other person. The absence of any explicit manifestation of this distress on their part is but a consequence of their being often incapable of communicating their pain. All measures capable of preventing, eliminating or attenuating pain should therefore always be adopted in relation to diagnostic or therapeutic procedures, as well as to an existing pathology. Particular attention shall be attached to the compatibility with pre-existent treatment. It is further necessary to bear in mind that, besides a physical pain there can also exist a psychological discomfort connected to the unfamiliar environment, and to being manipulated by strangers, and it can be manifested through a broad range of different modalities.

Some persons with autistic spectrum disorders shrink from every physical contact, as they experience it as an utter violence. Thus, also a plain objective examination can be difficult to be performed. Regardless of the apparent lack of understanding, all manoeuvres and procedures, even the most simple ones, should be preceded by a conversation with the patient, held after having devised an adequate description of what is going to be done and the available aids for reducing pain. It must be borne in mind that to perform diagnostic procedures - such as taking blood pressure, or vein puncturing - could turn out to be particularly demanding for these patients, and could require more time than usual. Occasionally, in order to perform certain diagnostic or therapeutic procedures, it may be necessary to sedate the patient. The use of pain sensors - as the ones used for smaller children - can help when dealing with adults with the above mentioned disabilities.

example

It can be particularly difficult to be able to perceive the presence and location of a painful symptomatology in persons with severe intellectual disabilities, or with autistic spectre disorders. Numerous problem behaviours⁵, as well as a number of emotional disorders, might be associated with the presence of pain. It is therefore essential for health professionals to cooperate with caregivers, who can be valuable sources of information.

⁵ According to the *Intellectual Disability Section* of the World Psychiatric Association, a "problem behaviour" consists of a behaviour which a socio-cultural milieu considers unacceptable, and which also causes stress, harm or disadvantage to the person enacting it, or to other persons, and requires an intervention of some sort. Within this context, the term "problem behaviour" includes other similar terms, such as "challenge behaviour", "behavioural disorder", or "behavioural problem/difficulty". Examples of "problem behaviour" are physical or verbal aggressiveness towards other persons or objects, or towards oneself; attempts at escaping, at repeatedly stripping off one's clothes, and screaming; or else generalised and persistent oppositeness.

example

In certain cases, patients with mobility impairments may present paraesthesia/anaesthesia, and thus they actually do not perceive any pain in certain parts of their bodies (mainly limbs). Consequently, a particular attention should be devoted to mobilisation manoeuvres, which can, also involuntarily, cause bone or muscular injuries. It must be further borne in mind that, during hospitalisation, mobilisation manoeuvres and the need to be aided - also for personal hygiene cares - by strangers, however qualified, can generate a serious unease in these patients.



ARTICLE 12 Right to Personalised Treatment

Each individual has the right to diagnostic or therapeutic programmes tailored as much as possible to his or her personal needs. To this end, health services must guarantee flexible programmes, oriented as much as possible to the individual, making sure that the criteria of economic sustainability do not prevail over the right to health care.

Persons with disabilities who need it shall be guaranteed the constant presence of a family member, or of a specialised professional - appointed by the family or by the person legally entitled to do so, or by the patient, if capable - to assist them in the diagnostic path.

example

For persons with intellectual disabilities or autistic spectrum disorders it is necessary to arrange, when hospitalised, all those measures capable of ensuring a round the clock presence of a family member or a specialised assistant, appointed by the family, who knows in detail the needs of these patients.

This person can act as a “liaison” to communicate with the patients with disabilities, thus allowing to determine their emotions and needs. It is important to recall that hospitalisation can be particularly hard for these patients and can aggravate their behavioural disorders.

In the case of persons with a mobility impairment, the presence of an assistant they trust, or of one provided by the hospital, who can support and help them, shall always be guaranteed. Instruments shall be fit for performing diagnoses for patients who are unable to rise from the wheelchair or bed, and functional to their specific aids.

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ARTICLE 13 Right to Complain

Each individual has the right to complain whenever he or she has suffered a harm, and the right to receive a response or other feedback. The health services ought to guarantee the exercise of this right, providing patients (with the help of third parties) with information about their rights, thus enabling them to recognise violations and to formalise their complaint. Said complaints must be lodged through standard procedures, and must be facilitated by independent institutions and/or by active citizenship associations, and cannot jeopardise the right of patients to start a legal action or pursue conciliation procedures.

“

In addition to the normal complaint connected to the health care administered, patients with disabilities are entitled to report possible shortcomings or anomalies concerning all aspects - including structural and architectural ones - which interfere with the enjoyment of the rights mentioned up to now.

It is furthermore essential for these patients to be given the right to participate in the prosecution and to be its protagonists, both as individuals, and through the organisation representing them.

”

example

Modules and information forms which allow them to lodge a complaint shall have to be prepared in advance for persons with sensorial disabilities.

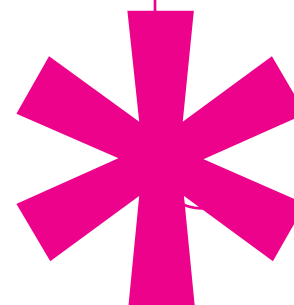
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ARTICLE 14 Right to Compensation

Each individual has the right to receive a sufficient compensation within a reasonably short time, whenever he or she has suffered physical or moral and psychological harm caused by a health service treatment. Health services must guarantee compensation, whatever be the severity of the injury and its cause (from an excessive waiting time, to a case of malpractice), even when the ultimate responsibility cannot be absolutely determined.

The presence of a previous physical difficulty shall in no way prevent or delay compensation due to anyone who was harmed, regardless of the cognitive, mobility or sensorial capabilities possessed at the time of hospitalisation.



ENCLOSURE 1

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Defining the Term “Disability”*

It is very difficult to define disability. The extension of its epistemological, social, political and health implications is instantly evident. This difficulty manifests itself through a multiplicity of definitions and reference models, also based on its scope of application. For a long time, the **medical** and **social** models represented the prevailing references and produced substantially diverse definitions.

The **medical model** viewed disability as a feature of the person, directly caused by disease, trauma or other conditions which produced an impairment. It was described as a limitation or loss of the capacity to perform actions which are essential for everyday life in ways considered normal for a human being. On the other hand, the **social model** interpreted disability as a problem linked to interpersonal relationships and integration within the social community.

In the last ten years, the diffusion of the **International Classification of Functioning** (ICF), drawn up by the World Health Organisation, has partially overcome this dichotomy imparting a radical shift to the concept of health and disability.

The *functioning evaluation* applies to all persons in dimensional terms, and no longer in terms of an improbable criterion of normality.

Prompted by a biological, psychological, and social integrated approach to health, disability is construed as the consequence or the result of a complex relationship between an individual's health conditions and personal and environmental factors, which represent the milieu wherein he or she lives. Hence, each individual, given his or her health conditions, can live in an environment whose characteristics can impair or facilitate his or her functional and social participation capacities.

The body structures and their related functions, the activities and the forms of participation enlisted by the ICF constitute the new reference also for the classification.

The United Nations Organisation, in the spirit of the ICF, in the *Charter of the Rights of Persons with Disabilities* defines them as:

“persons who present lasting physical, mental, intellectual, or sensory impairments which, interacting with different barriers, can hinder their full and effective participation in society, on an equal basis with others.”

Body structures and Functions

- Mental
- Sensory functions and pain
- Voice and speech
- Cardiovascular, haematological, immunological and respiratory systems
- Functions of the digestive, metabolic, endocrine systems
- Genitourinary and reproductive functions
- Neuromusculoskeletal and Movement-related functions
- Skin and related structures.

Activities and Participation

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self-care
- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social and civic life.

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CHARTER
OF THE RIGHTS
OF PERSONS
WITH DISABILITIES
IN HOSPITALS

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