



Presidenza del Consiglio dei Ministri
NATIONAL BIOETHICS COMMITTEE

BIOETHICS AND REHABILITATION

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PRESENTATION

Prompted by a request from the `Our Family Association`, whose main centre in is Ponte Lambro (Como), which conducts meritorious research, treatment and rehabilitation of persons with disabilities, the *Italian National Bioethics Committee*, in the plenary session on November 19th 2004, unanimously decided to enable a working group on *Bioethics and Rehabilitation*. The group was composed of the following members of the NBC, Professors Battaglia, Binetti, Bompiani, Borgia, Flamigni, Palazzani, Umani Ronchi; the appointed group coordinators were Professors Michele Schiavone and Maria Luisa Di Pietro. We are especially grateful to Professor Di Pietro, because she took on the burden to materially produce, after numerous group sessions, the final draft of the document, which was presented to the Committee in the plenary session on February 17th 2006, and then definitively and unanimously approved on March 17th.

Few will miss the importance of this text, which expands the traditional view of clinical bioethics, activating psychological, social and anthropological considerations of extreme importance. Attentive readers will notice how in these pages we do indeed emphasize the indisputable merits of "scientific" medicine, but we also and above all firmly maintain the immense importance of a commitment that is interdisciplinary, integrated and *humane* to the problem of disability with regard to its optimal treatment. Despite the lucid, coherent, and even sophisticated *doctrinal* dimensions of 'medical ethics and bioethics, the fact remains that no practicing of *care* may ultimately be true to itself if it is thought that it can only be rooted in the power of thought: it is the *encounter* with those who ask to be treated that is ultimately decisive: general good will and, even worse, warm, generous, but often ineffectual, emotionality, is of course not enough for the seriousness of this *encounter*. This NBC document wishes to call all those who operate in this sector and all those who have public health and welfare responsibilities to their cultural, social and even *epistemological* responsibilities. But, in addition, and this needs to be strongly emphasized, it also intends to call to mind that the authenticity of bioethics is expressed the moment it proves to be powerful enough to extend relational practice, able to sublimate the mere *being-with-the other* into the more difficult, but far more existentially authentic *being-for-the-other*.

President of the Italian National Bioethics Committee
Prof. Francesco D'Agostino

1. PREMISE

The issue of rehabilitation has been subjected to bioethical reflection only recently: for a number of reasons, including the late integration of this medical branch in the programmatic scheme of the International Health System and the complexity of the issue faced with different forms of disability and rehabilitation commitment. Moreover, the debate - specifically bioethical - the exercise of patient autonomy, quality of life, justice and allocation of resources, as well as the dramatic increase in the number of people with disabilities (as a result of road and work accidents and the rising average age of the population), have encouraged a systematic treatment of the subject only from the late 70's. There are, as a result, the first publications on the subject and the first declarations made by international bodies¹.

Among the obtained results there has been a gradual but irreversible disruption of the taboos associated with disability and rehabilitation, and a different approach - even linguistically - to the person with disabilities. In fact, no longer referred to as "invalid", "handicapped", "disabled" but rather "person with disability" in order to focus on the value of every human person regardless of his condition, and that the disability is not to be considered objectively negative but rather in relation to a physical, cultural and societal environment which is unable to exploit the possessed potential² (hence the term "differently able person" or "diversely able person"). The particle "with" also limits the connotation attached to the person stressing the fact that it is an achieved rather than a subjective attribute.

The different linguistic approach, in turn, has brought additional elements of justification to rehabilitative intervention, in particular, and the taking care of people with disabilities in general. Furthermore, "pre-occupation" for others has, in fact, always been conditioned by the recognition of their value and that of their being taken care of, even before being a question of *decisions*, it is, a matter of *vision*, i.e. the ability to see ' the other in his concrete needs as a human being.

¹ See, for example, the articles and items published in *Archives of physical medicine and rehabilitation* (1980), *Hastings Center Report* (1987) and the *Encyclopedia of Bioethics* (1978, 1995). Among the first international action, we recall the *Declaration on the Rights of Persons with Disabilities* United Nations (1975) and *Resolution AP (84) 3* of the Council of Europe - Committee of Ministers (1984), which summarizes the principles of social and cultural inclusion of the person with disability.

² As is known, the international classification of impairments, disabilities and handicaps (*International Classification of Impairments, Disabilities and Special Needs*, "ICIDH") proposed by the World Health Organization (WHO) in 1980, was the first attempt to overcome the traditional model that identified illness through a simple nosological classification and excluded any other element with the function to determine well-being. The ICIDH is based on three parameters that are closely related: 1. the functional damage (*Impairment*: impairment or organic lesion), 2. the loss of personal skills (*Disability*: partial or total reduction of ability to perform an activity), 3. the consequent existential disadvantages (*Handicap*: reduction of the holding of a role as a consequence of the *impairment* and/or *disability*). It is therefore evident that the person is not judged according to his ability to work alone but also to his potential resources that enable active social and relational participation. A reflection - as we shall see below - is developed parallel to the evolution of the concept of health.

2. THE REASON OF REHABILITATION

Even the concept of "rehabilitation" has undergone a transformation, over the last few years: developing from a medical-curative centered concept on functional deficiencies to an approach that looks at the person being rehabilitated in a comprehensive way in order to achieve an improvement in their quality of life.

In general, the term "rehabilitation" all therapeutic interventions (*treatments*) and welfare (*care*) that have as their purpose the (partial or total) recovery of impaired abilities (at different levels: mild, medium, severe) due to congenital or acquired pathologies (neurological, cognitive, psychic) and the valorization of existing potential (sensory, motor or psychic) to enable and achieve the best insertion and integration within the family and social context.

Rehabilitation deals with various types of people with disabilities: those with temporary impairments or those who are able to recuperate the state of bodily function prior to the trauma or disease or the onset of the severe and irreversible impairments.

Rehabilitation - we read in the Guidelines for rehabilitation activities approved in 1998 by the Standing State-Region Conference - is "a process of problem solving and education during which a person moves to reach the best level possible of physical, functional, social and emotional life, with the least possible restriction of operational decisions [...] about the rehabilitation process, concerns, in addition to strictly clinical aspects, also psychological and social aspects. To reach a good level of effectiveness of any proposed rehabilitation, for any individual, it must therefore be focused on multiple targets, planned in an orderly manner, so that the autonomy reached in different areas can result in the autonomy of the person as a whole and, in any case, a better quality of the person's life"³.

Rehabilitation may involve motor function, language, acquisition strategies, etc., and the choice of interventions –not always easy and immediate solutions - is performed according to the type of disability or disabilities that is prevalent, balancing both the strengths and needs of the person with disability. In fact, if you

³ And also in the same document we read: "Rehabilitation is also a process, describable as a set of actions aimed at countering the findings of deficits, to support achievement of maximum levels of physical, mental and social autonomy and to promote psychic well-being and the widest expression of affective and relational life. In such a global vision rehabilitation thus becomes a process that articulates skills, networking services and integration between health and social rehabilitation and as such is a right that must be enjoyed throughout the national territory and therefore any shortcomings must be punished but systems should also be activated to incentivize and reward. It should be stressed that proper implementation of rehabilitation strategies produces substantial savings in follow-up actions and the resources required should also come from a rationalization of interventions based on surveys of local needs and availability, the rigor of the methodologies and data in scientific research. Each intervention of rehabilitation before being generalized must pass the test of scientific validation: people or families can not be deceived, nor asked to pay for services whose effectiveness has not been proven. Health and social funds can not be directed to interventions of unproven efficacy, while interventions of proven efficiency remain without funding. Rehabilitation is therefore a global process so that integration between health and social services becomes essential "(Standing Conference Measure for representatives of the State, Regions and Autonomous Provinces of Trento and Bolzano, May 7th 1998 in the Official Gazette of May 30th 1998, n. 124).

do not take into account the needs of the person with disabilities, you run the risk of achieving only a reduction of the disability to the extent that there is the extreme possibility of inducing others.

The term "rehabilitative medicine", instead, indicates - on the one hand - all the operators of instruments and techniques dedicated to medical rehabilitation, and - on the other - a discipline with its theoretical basis and practical applications.

Therefore, next to medical rehabilitation (defined as prevention, containment or removal of disability), it is possible, then, to identify - even if the distinction is not always clear cut - social rehabilitation which has as its purpose the prevention and demolishing of barriers. In fact, rehabilitative intervention, while having an immediate horizon located in the injured and dysfunctional body, also has a wider horizon and this is the whole personality considered by itself and as regards family, social and occupational inclusion⁴.

We could therefore, think of rehabilitative medicine as four concentric circles - proceeding from the inside out - namely: 1. the injured organ and its dysfunction (primary damage); 2. prevention of secondary damage (e.g. developmental delays in children and adult functional imbalances) and tertiary (e.g. position defects, deformities, painful and dystrophic syndromes resulting from inactivity); 3. the totality of the person in all his physical, mental, moral and spiritual components; 4. Society is called on to prevent, provide resources, personnel and facilities and to elicit a clear desire for solidarity⁵.

Rehabilitative intervention has found, therefore justification in the evolution of the concept of health, which - as is known - has received different interpretations over time which has influenced the aims and methods of health intervention. Given that outlining the concept of health - as indeed the specular concept of the disease - is somewhat complex and not unique⁶, it is possible to schematically identify at least three paradigms:

a. HEALTH AS AN "ABSENCE OF DISEASE." According to this paradigm, health is equivalent solely to the condition of physical efficiency or absence of disease, and the request - implicit or explicit - of the patient to return to the pre-existing condition prior to the onset of the morbid condition. In this perspective, the only purpose of health intervention is the diagnosis and treatment of the disease in order to eliminate the physical symptoms. This is an organismic vision that not only does not affect the other dimensions of the person (mental, spiritual, social) but which also reduces the disease to an incidental event in the life of the subject.

b. HEALTH AS A "STATE OF COMPLETE WELL-BEING." The World Health Organization - in 1946 - defines health as "a state of complete physical, mental

⁴ The above is justified even in art. 3 of the Constitution, which - after repeating the equal dignity of all citizens - states: "[...] and 'It is the task of the Republic to remove those obstacles of an economic or social nature which constrain the freedom and equality among citizens, prevent the full development of the human person and the effective participation of all workers in the political, economic and social development of the country'".

⁵ E. Sgreccia, *Bioetica, handicap e riabilitazione*. In *Manuale di Bioetica. Aspetti medico-sociali*, vol. II, Vita e Pensiero, Milan 2002, p. 459.

⁶ C. Boorse, *Health as theoretical concept*, *Philosophy of Science* 1997, 44, pp. 542-573; D. Engelhardt, *Health and disease. History of a concept*. In Reich W. (ed.), *Encyclopedia of Bioethics*, Mac Millan, New York 1995, vol. II, pp. 1085-1092.

and social well-being and not merely the absence of disease or infirmity"⁷ - This definition looks at the person in a global sense (physical, psychological and social) and exceeds the organismic view of health, it must be thought out and promoted through projects that embrace physical, psychic and social well-being. The same medicine, which once occupied almost exclusively the cure of disease, is expanding the possibilities of intervention: from diagnostic-therapeutic medicine to also rehabilitative medicine. On closer inspection, however, the WHO definition, while having the advantage of presenting a proposal with a multidimensional and holistic vision of health, can promote a reading of health as efficiency contributing also to create unrealistic expectations about the possibilities of the same medicine. Health as a state of complete physical, psychological and social well-being may in fact never be realized or realized rarely with the risk - not just theoretical - of overly extending the boundaries and to be confronted with demands that have nothing to do with the pathology itself.

c. HEALTH AS "BALANCE". If one looks globally at man, health and illness do not seem extrinsic factors to everyday experience but rather subjective experiences. Health thus becomes a kind of *balance* in the flow of everyday experience: a quiet *balance*, a *balance* that is not static but dynamic an intrasomatic equilibrium, intra-and inter-personal. The alteration of this balance can cause illness, illness which no longer takes on the characteristics of a simple incident, but it becomes an opportunity to seek a new balance through a process of growth, awareness and responsibility. The person becomes healthy to the extent that he is capable of living in a conscious and free manner, exploiting all the energy in his possession. The person is, by contrast, ill or incapable, or not sufficiently able to manage his life in a conscious and free manner, and exploit his skills and energies. This being understood, health is not a fact: it is an achievement; it is not acquired once and for all, but should be continuously sought; it is a task, a lifestyle, which is enhanced by the ethical dimension that encompasses the other (organic, mental, and environmental) dimensions. It is in this sense that health is also defined in relation to non-medical factors (nutrition, working conditions, housing, etc.) which may be affected by individual and collective choices. It is in the light of this interpretation of the concept of health that, in addition to diagnosis, treatment and rehabilitation, prevention also has its part, and is aimed at encouraging behaviour that can prevent the onset of diseases and/or break down of psycho-physical balance. The promotion and protection of health becomes – not just a right – but first and foremost, a real duty, which is made real through prevention or cure to recuperate health, as far as possible, when disease has already compromised it. The paradigm of "health as a balance" does not intend to deny or question that advances in Medicine are due almost exclusively to so-called Scientific Medicine, that is, the set of doctrines and remedies based on scientific assumptions of the proposed treatments and rigorous

⁷ Subsequently, the World Health Organization has included the concept of reproductive health: "Reproductive health is a state of complete physical, mental and social well-being not just the absence of disease or infirmity, in all areas related to reproductive system and its functions and processes". To this central issue even in the discussion on disability, the National Bioethics Committee reserves the right to dedicate a subsequent document.

testing regarding both successes, and failures even in rehabilitation⁸. There is, however, the will to highlight how the same Scientific Medicine is the appropriate response to the health needs of man, but that it should be accompanied by a "global" system that permits even other dimensions of the "good" of the person to emerge.

Even the inclusion of non-medical factors in the concept of health has made it possible also to develop an important distinction between disability and illness, the WHO, discharging the *Classification of Functioning, Disability and Health* (ICF as abbreviated in English) as a model of cultural approach to disability, has emphasized that disability is a characteristic that belongs to all mankind. It is in a bio-psycho-social perspective that therapeutic and curative intervention is reformulated, rather than concentrating only on medical factors, highlighting the impact of a hostile environment and a non-inclusive society. The approach to achieve the condition of equilibrium or health becomes so personalized, and is related to the life⁹ and relational environment.

This document does not examine individual clinical situations (Table 1) or the variety of rehabilitative interventions available today, but will present only elements of reflection on rehabilitation in general and on bioethical issues related to it. Neither does it enter into the delicate and complex area of psychiatric rehabilitation, to which the Italian National Bioethics Committee will devote a subsequent document to follow on from the previous one on "Psychiatry and Mental Health: bioethical guidelines", published in 2000.

⁸ Cf. Italian National Bioethics Committee, *Aims, Risks, and limitations of Medicine*, Rome 14th of December 2001.

⁹ Interesting is the definition of the assumption of responsibility "care for people with disabilities" first developed by the National Conference on Handicap, Rome, 2000, the "care for people with disabilities" expressed as "the *continuous and integrated process* by which there must be assured the *governing of all the coordinated interventions on the conditions which hinder their inclusion in society, education and work*, and is aimed at encouraging the most complete unfolding of the personality of individuals. In a framework based on the new WHO classification ICIDH-2, the taking of responsibility should be defined as *the strategy of attention of care services, evenly distributed on the territory, to the disadvantaged condition of persons with disabilities*. This strategy of attention must be carefully manifest through the provision of public or private services, in coordinated interventions, and with the necessary continuity, having the purpose of *enhancing the skills and abilities of people with disabilities* and to work with the appropriate resources and skills for the achievement of equality of conditions among citizens by limiting or eliminating social and cultural discrimination. The taking of responsibility is one of the key moments for the establishing and maintaining of the relationship regarding person/family/service system/and social context. It is therefore a process that, respectful of individual choices of people with disabilities and their families, is influenced by the extent and quality of existing resources, the levels of integration between services and institutions as well as their ability to ensure continuity with the consistent evolution of life's course. It is then a process that requires careful attention to the intervention of broad interinstitutional expression and in the stages of evolutionary transition of particular significance, such as childhood/adolescence, or adolescence/adulthood".

3. REHABILITATION AS A BIOETHICAL PROBLEM

At the moment of planning one or more rehabilitative interventions on a person, there are some obvious common elements that can be summarized as follows¹⁰:

- **historicity:** intervention must be closely linked to the diagnosis and take account of any rehabilitation, educational or therapeutic rehabilitation that has already been carried out;
- **globality:** to take charge of the care of the person always involves both the emotional and cognitive side;
- **personal involvement:** the success or failure of rehabilitation interventions is directly proportional to the active participation of the person concerned and / or his family to the project, the degree of commitment and depth of motivation;
- **pursued objective:** that is the improvement of the quality of life in a perspective that regards the whole span of life, which requires not only a prior evaluation of disability and existing potential but also the needs of the person and available resources. It is a question of human resources (the person with disabilities, the family, friends and health professionals, teachers, etc.) and material resources (tools, space, organization of time);
- **timely planning:** a rehabilitative intervention should be based on a theoretical scientific model according to which realistically achievable goals are set in the short and long term, appropriate methodologies and work tools and methods of verification of achieved results. A lax approach could, in fact, lead not only to little or no effective intervention, but also the belief that nothing can be done, and reduce the strength of that key factor which is motivated commitment.

¹⁰ M. Zanobini, M.C. Usai, *Psicologia dell'handicap e della riabilitazione*, Franco Angeli, Milan 1997.

<p><u>Categories of Impairments</u></p>	<ul style="list-style-type: none"> - <i>Intellectual disabilities</i>: these include intelligence, memory and thought - <i>Other psychological impairments</i>: include impairments that interfere with the basic functions of the constituents of mental life (consciousness, perception and attention, emotional functions, patterns of behaviour) - <i>Language impairments</i>: refer to the understanding and use of language and its associated functions, including learning. - <i>Hearing impairment</i>: not only refer to the ear, but also to the structures and associated functions. The most important subclass consists of impairments that relate to the hearing function. - <i>Eye impairments</i>: do not refer only to the eye, but also to the structures and associated functions, including the eyelids. The most important subclass consists of the visual function. - <i>Visceral impairments</i>: include impairments to the internal organs and other special functions. - <i>Skeletal impairments</i>: include mechanical and motor disorders of the face, head, neck, trunk and limbs. Excluding more obviously disfiguring impairments. - <i>Disfiguring impairments</i>: include those impairments with the potential to interfere with or disrupt social relations. Conditions that may not be the result of specific diseases affecting the control of bodily functions are included. - <i>Generalized impairments, sensory or other</i>: include multiple impairments, serious impairment of continence, metabolic impairments, and sensory impairments of various body areas.
<p><u>Categories Of Disability</u></p>	<ul style="list-style-type: none"> - <i>Behaviour disability</i>: refers to an individual's awareness and ability to behave, both in daily activities and in relations with others, and include the ability to learn. - <i>Communication disabilities</i>: refers to an individual's ability to generate and send messages and receive messages and understand. - <i>Personal Care disability</i>: refers to an individual's ability to fend for themselves with regard to basic physiological activities, such as the evacuation-urination, nurturing, self-care, hygiene and dressing. - <i>Locomotor disability</i>: refers to the disability of the individual to perform tasks associated with movement, both of oneself and that of objects from one place to another. General mobility and consideration of the degree to which it can be recovered with aids are excluded. - <i>Disabilities in the use of the body</i>: refer to an individual's ability to perform typical activities associated with the use of body parts and derivative activities as the execution of tasks associated with the residence of the individual. - <i>Dexterity disability</i> : refers to the dexterity and skill of body movements, including manipulative skills and the ability to adjust control mechanisms: The ability to write or use signs is precluded. - <i>Situational disability</i>: these have been included for practical reasons, particularly with regard to reciprocal specification of the environment. - <i>Special skills disability</i>: include individual skills and talents required by professional relocation, such as behavioral skills (intelligence, motivation, perception, learning ability, memory, etc), ability to perform tasks

	(programming tasks, solve problems, etc.). - <i>Other limitations of the activity</i> : include unmet needs in other parts of the classification.
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Table 1. Classification of impairments and disabilities (Capodaglio, 1995).

It follows that the issue of rehabilitation - although all the criteria of legitimacy that apply to any diagnostic and therapeutic choice remain valid – submits itself to bioethical reflection with some distinctive characteristics that differentiate it from other areas of medicine:

- the necessary and constant reference to a global vision of the person with disability perceived not only in the totality of his being but also as someone inserted in a particular socio-environmental situation, from which it is impossible to parcel out the person and/or his disability or give a "reading" outside the context of life and relationships;
- the dilation of time as rehabilitative interventions may be prolonged over a period (months, years), making the priority the re-reading of methods of communication and the obtainment of consent and continued involvement - even in terms of motivation – of the person with disability: it is a progressive process with constantly updated achievement of results;
- the multiplication of those involved even as a result of the involvement also of the family of the person with disability. And, especially in the case of a child, the family itself becomes a participating collaborator in the rehabilitation process;
- the unpredictability of the results due to the dynamism of rehabilitative interventions and the difficulty of quantifying existing and hidden potential in the person with disabilities which - often - exceed expectations. It is for this reason that all persons with disabilities should be considered in their uniqueness and excluding the limitation in order to apprehend what they can give.

Bioethical reflection is, then, called into question at different levels: anthropologically (in determining the meaning of the body, and therefore impairment of the body), on an ethical level (in identifying reference criteria for those involved in rehabilitation, directly involved in determining and implementing the rehabilitation program, and for the person with disability, whose autonomy may however be limited or conditioned), at the judicial level (in identifying the person with disability as a subject with rights) and on a political and social level (in planning and allocating resources to invest in rehabilitation and the planning of intervention directed at the inclusion of the person in the community).

4. THE HUMAN CORPORALITY AND EXPERIENCE OF LIMIT

The *ethos* of the experience of disability is , the body, perceived not as an "object" in its raw facticity but rather as a body that is "lived", and "personal", that body in which and through which we exist, in actual fact the body that we are. It is worth recalling here Husserl's famous distinction between *Körper* and *Leib* , where *Körper* indicates the body as a simple object and *Leib* indicates the lived body or

the awareness of one's own body, and Scheler between *Geist* (the spiritual world), *Ich* (the psychic world), *Körper* (the physical world) and *Leib* (the unitary form of all organic sensations).

The "lived body", could also be defined as "corporality", precisely to show the whole of human subjectivity under the aspect of its bodily condition as constitutive of its personal identity. It is specifically this lived body that becomes the crossroads of the encounter and interchange of the multiple dimensions of the person: through the body the person can express himself, it is through the body that every interpersonal relationship is possible, through the body one finds a place in the world, and is added to the flow of human time.

Man – as Hengstenberg wrote - "is not just an animal organism with the addition of consciousness which elevates it. Man is 'the only being who has a body, while in the animal we can only talk about organism[...]. The addressing of objectivity (or the sense of objectivity) has cooperated in the morphology of the limbs and human organs, and the same applies for the body"¹¹.

As an experience of a personal body, disability is not just about physicality or just the psyche. Any impairment of somatic integrity or functionality has, more or less serious repercussions on the psyche, influencing the definition of body image, the structuring of personal identity, personal way of relating to others; but in the same way any impairment or alteration of the psychic sphere involves different reflections on the perception of one's corporality and physical integrity, to our being in the world and entering into relations with others and, therefore, on the construction of the self and the definition of one's identity. The 'I' that lives, feels, understands, suffers, hopes is spiritual and corporeal combined together.

On the other hand, the experience of the limitation that disability inevitably implies is not an experience extraneous to human existence, indeed the opposite could be said, that is, that the limitation is an essential dimension of human experience. As Nussbaum correctly writes, "we must not think about the needs of adults and children with disabilities as something that refers to a very particular condition of life, easily distinguishable from the cases that "are classed as standard" It is, instead, a situation full of implications also because of the way we think about our parents when they grow old, and the needs that we ourselves will probably have if we live long enough. As life expectancy grows, the relative independence enjoyed by many of us ends up appearing as a condition that is only temporary, as a stage in life which we gradually enter, but that we all are going to leave all too quickly. Even during the prime of life many of people come to experience long or short periods in which they are forced to live in a state of extreme dependence on others - such as after surgery or after a serious injury, or during a period of depression or severe stress"¹².

Not expressible in terms of acceptance or rejection, the experience of limit is clear and constitutive of human nature itself: "That man has an "I" that can not leave the course of dramatic action into which it was born, and he can not leave to

¹¹ H.E. Hengstenberg, *Philosophische Anthropologie*, Pustet, Munchen- Salzburg 1984, pp. 81-82.

¹² M. Nussbaum, *Giustizia sociale e dignità umana*, trad. it., Il Mulino, Bologna 2002, pp. 30-31.

consider what to play. He is now in the game, without his ever being asked if he wanted to play"¹³.

The limit is, therefore, part of its objective dimension of human experience, but as it is a completed life experience it involves an alteration of life and subjectively also forces to rethink one's potential. In this sense, the experience of limit is not an experience of what is absent but rather of what is possessed and the limit of disability should not be read as a listing of what is "missing" but enhancement of what is possessed.

If these conclusions are accepted to be shared, it follows that the existential value to be pursued in rehabilitation is that of enhancement of the person. In fact, in disability difference can be concrete related to the ability to do or not do something, to perform or not perform a certain task, but it does not exist as regards a person's value, the right to be human, or in the dignity of being called by one's name. And it is precisely from these considerations that there has been - as mentioned in the premise - an evolution of the concept of handicap, not only a semantic evolution but an evolution in both content and anthropological foundations.

See in this regard, the aforementioned features of the *International Classification of Functioning, Disability and Health* approved by WHO in 2001, where disabilities are described in a different way, in reference to the environment in which a person lives with their own abilities, large or small as they may be, and - as already mentioned - the terms "handicap" and "handicapped" disappear, and are replaced with the term "disability", "activity", "social participation" and "person with disability" or "differently able person". Terms, which have always had a negative connotation, consequently acquire a positive valence and interactions between the various factors that constitute health or disability have become more complex, making it possible to understand particular situations and also give due regard to the context, both personal and environmental. The assessment of health status can not then be made ignoring the complex relationships between mind, body, environment, contexts and culture.

Among the positive consequences of this approach, there is no doubt the belief that if a person can not - for example - move, is actually the world around him not able to accept him. We are no longer then, faced with a "motor disabled person" but rather a "person who can not climb if the house does not have a ramp" it is not the limitations of the body that should concern us but rather the reasons why it is not possible to participate in social life. This change requires the removal of the sense of being a "bearer of disadvantage" to people with different abilities, but rather to evaluate them according to abilities and *performance*¹⁴. We must,

¹³ H.U. Von Balthasar, *Teodrammatica. II. Le persone del dramma: l'uomo in Dio*, Jaca Book, Milan 1992, p. 323.

¹⁴ The first signs of this approach are already evident in the document *Rules for equalizing the opportunities of persons with disabilities* (1993) of the United Nations, consisting of 22 rules that "apply to support the process by which the various systems of society, the material picture, services and activities and the information is made accessible to all, especially to people with disabilities.." It appears clear, therefore, how the idea of "social disadvantage" of people with disabilities is increasingly outlined, and that it should be tackled with the same intensity with which physical rehabilitation is provided for. These principles have been stated more clearly in 2002, within the document *Examination and evaluation of the world programme of action concerning*

therefore, work by providing everything that can lead to full participation in the social and relational life of each person and at the same time, try to break down every barrier that prevents the full exploitation of the different realities in the social fabric. This objective that goes beyond the concept of "integration" is expressed in terms of "inclusion".

Indeed, "social inclusion" is very different from "integration": while "integration" means the inclusion of people in an established context of rules and principles and the person with disability has to adapt to what has already been decided by the community that integrates him, inclusion, however, is based on the participation of the individual in the decision-making and planning of the whole community that takes into account cultural, religious and psycho-physical diversity of the person entering the community. The role of the person with disability is thus equal to that of other individuals who are already included. This approach rejects any form of institutionalization as a discriminatory approach that has produced the social and individual depletion of persons. In fact, the separate paths of rehabilitation - in special and segregated places- inevitably reduce the relationship with society, and imposes perception models of inadequacy and inability and exclude people with disabilities from having the possibility of equal exchange of experiences and skills.

Another new element, present within the international documents of European and international agencies, is the approach to people with disabilities based on respect for human rights¹⁵. People with disabilities, particularly serious

disabled persons which – on presentation to the General Assembly – has formed the basis for the *Resolution A/RES/56/168 and the subsequent approval of the International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities* (www.un.org/esa/socdev/enable).

¹⁵In the field of human rights, see: the *Declaration of the Rights of Persons with Disabilities* (1975) of the United Nations (Articles 3. And 10 states that the "handicapped person" is entitled to respect for his dignity and must enjoy the same fundamental rights of citizens of the same age), the *Convention for the Protection of Human Rights and Fundamental Freedoms* (1950) of the Council of Europe (art. 14 settled the condemnation of all forms of discrimination, which leads to include - though not explicitly - the discrimination of the person with disabilities), the *European Social Charter* (1996) the Council of Europe, - developing the principles of the Convention of 1950 from an economic and social aspect - states the rights of persons with disabilities to be integrated into general education, teaching and training by limiting the use of specialized facilities to cases of necessity, to be assured access to the labor market in a fair manner and be guaranteed that States will implement all necessary measures to overcome obstacles to integration and social participation, and the *Recommendation R (92) 6 for the construction of a coherent policy for people with disabilities and the Resolution AP (95) 3 on the professional assessment of the handicapped* Council of Europe, inspired by the examination of "capacity" rather than "disability" (incapability); *Resolution* of 17th June 1999 of the Council of the European Union, which calls on States to strengthen their national policies in this regard, and in relation to persons with disabilities, and the *Charter of Fundamental Rights of the European Union* (2000), which in articles 21 and 26 reinforce the principles of interdiction of any discrimination and calls for respect for the rights of persons with disabilities to participate in community life. It appears, therefore, clear that internationally there has been constant attention to ethical and legal issues, particularly – in the first phase – to the affirmation of rights without any distinction between types of causal onset but rather to the capacity of recovery, and - in a second phase – to implementation of full participation in social life including work [see, also documents the International Labour Organization - ILO Convention-including *Convention n. 159-1983* and the Document *Collection of practical guidelines for the management*

ones, having become invisible citizens due to segregating treatments and social exclusion, are often discriminated against and are without equal opportunities compared to other citizens, in addition to which there is a continued violation of actual human rights¹⁶.

5. ETHICAL INTERPRETATIONS OF REHABILITATION

In the context of bioethical reflection on rehabilitation, it is possible to identify the best method of approach, which moving from specific readings of the meaning of the body and the person, subsequently, go on to propose different solutions on the ethical, legal, political and social level.

➤ Functionalist approach. Rehabilitation is seen as a health practice that has as its goal the identification of technical tools and procedures necessary to enable a person to recover only in terms of physical efficiency and autonomy, neglecting the other personal dimensions (psychological, emotional, relational, etc.) and not taking into account the social and relational environment. It is an approach that mostly considers the human body as a material entity separate from the personal dimension and evaluates the person with disability only on the basis of his functional capabilities. The ethical, legal and socio-political consequences of this approach may concern, above all, those who are in situations of extreme physical frailty. Since the feasibility and the establishment of a rehabilitation program (and the related allocation of resources, economic and human resources for this purpose) would depend on the valuation of real or foreseeable possibility of recovery in terms of efficiency and autonomy, those who seem - for clinical conditions - unable to do so may not be appropriately considered and therefore, would be left out of social policy. This shortage would then be filled by spontaneous and, therefore, occasional, charity and solidarity inspired by feelings of sympathy or social opportunity.

➤ Contractarian approach. The contractarian approach moves from respecting autonomy (in the sense of full capacity of self-awareness, self-

of disability in the workplace (2001)], as a right belonging to every person even those with disabilities work is a condition included in the defining of the concept of human dignity).

¹⁶ As regards the Italian situation, this reaffirmation of rights is already listed in the Constitution, where it is claimed - among other things - the principles of removing barriers that limit the full development of human personality. The course of implementation of rights in terms of legislation has not always been easy, but it is a fact that it has reflected the evolution of conceptual and cultural models of disability over the years. An important step - among many - was, however, the approval of Law No. 104/1992 (*Framework Law for the assistance, social integration and rights of disabled people*) in the Ordinary Supplement to Official Gazette of February 17, 1992, No 39). As regards - in particular - rehabilitative intervention, article 5 paragraph c, reads: "The removal of the invalidating causes, promotion of autonomy and the achievement of social integration are objectives pursued through the following [...] to guarantee the timely intervention of therapeutic and rehabilitative services, to ensure the recovery consented by scientific knowledge and techniques currently available, the maintenance of the handicapped person in the family and society, his integration and participation in social life.

determination, rationality of the individual able to stipulate contracts and exchanges with other individuals, in conditions of symmetry and reciprocity) and attaches to rehabilitation a predominantly autonomous and individualistic value. Consequently, the planning of rehabilitation (in inter-individual and social terms), on the one hand, depends on the autonomous choice of the person with disabilities – a choice in itself that is not always possible – and on the other hand, closely related to the expectation of recovery of full capacity for autonomy in the sense of self-sufficiency, self-awareness and self-determination of the individual. To the extent that this objective is not considered accessible, because there are no conditions to achieve it, to do so, the cost of rehabilitation would not be considered justifiable.

Both the functionalist approach and the contractual approach can produce - absurdly - two completely opposite outcomes: the "abandonment" of rehabilitation' and "aggressive" rehabilitation. Indeed, insofar as it is believed that the person should be rehabilitated only in anticipation of the total recovery of efficiency and autonomy, it can result in a defeatist attitude (the decision not to activate a rehabilitation program in the case of the desired objective not being reached and the benefit obtained does not justify the cost and human commitment) or - by contrast - an overly interventionist attitude (choosing to activate all possible and available resources to achieve the objective at any cost, even if there are no objective conditions of total recovery, in a race for efficiency, productivity and autonomy at any cost).

➤ Human rights-based approach. Since people with disabilities often live in conditions of discrimination, the aim of rehabilitative intervention and "enabling" intervention is to restore the condition of parity, in terms of opportunities, that are the right of the human person regardless of his condition. The "enabling" attribute indicates that there is no need to restore the impaired function of the body, but rather, to acquire the ability to perform the activities associated with it even if in different ways. For example, in the case of the inability to walk, rather than insist on achieving a standing position – if, at all achievable - rehabilitating the person to achieve this standard of mobility, one can intervene to make the person acquire a new skill linked to the use of a wheelchair: and this choice does not change, of course, his dignity as a human being. This new cultural approach focuses on *empowerment* of the person with disabilities¹⁷, which starting from the person's functional limitations, develops paths of growth, awareness and the acquisition of skills and abilities that enhance their independence and the ability of self-determination, promoting their social inclusion. In addition, new forms of support

¹⁷ The essential tools of *empowerment* are education and information, the enhancement of skills and abilities, the change of perspective and perception of one's condition, produce stimuli and motivation to change life. The *empowerment* for disabled people covers several aspects: emotional (reformulation of emotions to build and transform rather than to limit and destroy), perceptual (re-definition of life experiences on the basis of the social model), intellectual (understanding of the cultural tools to be acquired and the learning of their language), behavioral (transformation of human and social relations on the basis of the new awareness), enabling (learning to do things in a different way), rehabilitative (changing the way we do things by introducing new approaches). The main instruments of action are the personalized projects of life, drawn through the active participation of the persons concerned.

are also developing, not least the *peer counsellor*, the availability of personal assistants, and the use of ever new technologies¹⁸. This approach, which moves from the recognition of the value of the person regardless of his condition and that, in the case of a person with disability, aims to increase the chances of self-determination, autonomy, independence and inter-independence, is extremely appreciated. At the same time, however, it puts forward some questions on bioethics: to what extent and by what methods should one intervene in the course of rehabilitation? In order to obtain informed consent is it necessary to provide a person with information even on possible alternatives to the traditional rehabilitation model (for example, using a wheelchair instead of rehabilitation - possibly - to walking)? How should the rights of persons with disabilities be respected when they can not represent themselves? When and under what conditions is there a non-proportionality of rehabilitative interventions to the extent of producing talk of "aggressive rehabilitation"¹⁹?

➤ Integral approach. The integral approach regards rehabilitation as a set of interventions (not only medical) that move from the taking charge of the whole of the person with disabilities, considered in the totality of components, and not only in its mere physical dimension. Indeed, ability itself is not simplistically identified as "normal" functionality. On the anthropological level the corporality is perceived in the meta-biological dimension, irreducible in its parts since the same human organism is more than the sum or juxtaposition of parts, and the person is to be recognized in his dimension of being, irreducible to exterior expression and serial functions or capabilities that do not exhaust "the" subject but they are "of the" subject. According to this view, the subject pre-exists those same functions, it is the indispensable substrate for their manifestation, the function is actualized as a consequence, moreover, partial and incidental, which presupposes the existence of a human person as a whole (abstract qualities do not exist; there are only the concrete determinations of a specific existing embodied entity).

The integral approach to the person with disability, in this way, moves the barycentre from appearing to being and recognizes the immeasurable value of man regardless of the functions he is able to carry out: the absence of certain

¹⁸ See - for Italy - Law 328/2000 (*Framework law for the implementation of the integrated system of interventions and social services*), as art. 14 reads: "To achieve the full integration of disabled people in art. 3 of Law 5 February 1992 n. 104, in the context of family and social life, as well as courses in education or vocational education and work, the municipalities in consultation with the local health units, shall provide, on request, an individual project, as established by paragraph 2. 2. Within available resources according to plans laid down in Articles 18 and 19, the individual project includes, in addition to evaluating diagnostic and functional performance of treatment and rehabilitation paid by the NHS, the services of the person provided by the council in a direct and accredited form, with particular reference to recovery and social integration as well as the economic measures necessary to overcome poverty, marginalization and social exclusion. In the individual project the potential and any potential support of the family are defined [...]" (in the Ordinary Supplement to Official Gazette of November 13, 2000, No. 265). And again: Law n. 4/2004 *Provisions to support the access to information technologies for the disabled* in the Official Gazette of January 17, 2004, No 13).

¹⁹ See: Disabled Peoples'International - Europe, *Dichiarazione di orientamento sulla nuova genetica e le persone con disabilità*, 2000.

functions (transient or permanent) does not, therefore, negate, personal existence that remains such by nature of the fact that it pre-exists qualities. It is the body of the person with disability in "residuality" conditions (no longer being) or in a condition of "deprivation" (never being) – that is to say, of non-implementation, temporary or permanent of certain functions (due to the presence of external or internal factors that prevent its manifestation) – that does not negate the nature of being. It follows that the subject with disability, is always and nevertheless a person, because even though he is in existential conditions which prevent the manifestation of certain properties or behaviour, the lack of functions does not modify nature. There is the primacy of being a person over that of becoming a body.

The integral approach founds, on an ethical level, the duty to respect those who do not fully exercise their skills and abilities: the bioethical question arises because there are existential conditions of fragility and weakness in which one can not live without the help of others. In these cases health care and biomedical practices have to deal with those who are not able to live the fullness of the potential inscribed in human nature. The being a person imposes itself even for those who can not decide, think, feel, understand, and therefore, also for the person whose abilities have been diminished or reduced: in this sense it captures the scope of the doctrine of human rights, which are intrinsic to the person and not a mere consequence of their recognition. If it is true that every man is a subject of rights, it is starting from his corporality, whether ill, deformed, inert or unconscious, that he deserves protection. The law is then called upon to defend the equality of men: in this sense the body, every human body is bearer of an objective right, it is a "strong" legal otherness that asks to be recognized and to which every man has a debt (even apart from the recognition of one's entitlements).

Even the person who is no longer able to claim their rights, who is in an existential condition of impairment, who needs the help of others to exist and to improve his condition, "calls for" the protection of the law.

6. INTEGRAL APPROACH AND REHABILITATION

In the light of a integral approach rehabilitation is not only planning of therapeutic and care interventions for the recovery of (sensory, motor, cognitive) functions, but it is a global project for the person with disability that involves several levels: physical, psychological, ethical and spiritual. Rehabilitation thus becomes a dynamic project, an ongoing process, which should always be able to readjust to the objective situation: diagnosis allows definition (sometimes not so accurately) of the initial condition (through the identification of the pathological cause and consequences that it has produced on the individual, distinguishing primary, secondary and tertiary damage), but it is not always possible to establish a precise prognosis (either in terms of time, or in terms of future results). Rehabilitation is an often long and arduous journey on a winding road or uphill, where often the ultimate goal can not be seen. This is a course of action that presupposes relationality (in terms of collaboration, trust, solidarity and support)

those starting out on their journey include: the person with disability, the doctor, rehabilitation therapists, and family.

Moving, therefore, from the assumption that a person - even in conditions of residual life (i.e. of not full manifestation of ability, now or expected in the future) - is a fully- fledged person, endowed with dignity in the strong sense and rights in the same way as any other man, and that dependency is a constitutive dimension of the human being (we always depend on others, to varying degrees in our lifetime), rehabilitation is to be considered much more than merely a biomedical practice: to "rehabilitate" means to activate a series of therapeutic interventions but also and above all human, on the individual body. It is for this reason that one should always take into consideration the overall good of the person with disabilities, in the recomposing of his structural balance. Based on the empirical evaluation of what is predictably recoverable regarding the objective disability, it is essential that the activation of the recovery strategy arises from the sharing of the project, from a "rehabilitative" alliance stimulated by continuous dialogue and mutual cooperation of all the parties involved.

It is essential that the physician, with appropriate gradualness, tells the person with disability, and – where possible, subject to his consent - the members of his family about the objective conditions of the impairment and the predictable possibilities of recovery: it is then up to the physician and rehabilitation therapist (as well as the family members) to help the person with disability to accept their condition, to understand that health is not full physical, psychological, and social well-being, but - as already stated - a dynamic equilibrium able to adapt to different situations, to accept limitations and reorganize daily life and relationality with others precisely on the basis of conscious awareness (which is neither unconscious removal nor resigned acceptance) of the limitations. The person with disability should also be helped to accept the eventual impossibility of recovering the original state of full functionality, by motivating him to undertake rehabilitation and by avoiding on the one hand, the giving of hasty guarantees of assured success, and, on the other hand, the suppression of hopes for improvement where these objective conditions may exist.

In this context, the role - in particular – of the rehabilitation therapist is not only technical: it is not just to restore the use of a function of a limb, organ or capability, but also to establish a continuous human relationship with the person with disability in a condition of vulnerability and fragility. Rehabilitation is not an action that the person undergoes passively (e.g. surgery), but rather it requires active interaction of both parties: the rehabilitation therapist who work and the person with disability who actively participates. In this sense, the inner motivation and personal commitment to recovery are an essential and crucial element for a good result, to the extent that, not only can the use of affected functions be recovered, but also in order to evoke residual potential and mobilize inner compensatory energies.

Psychological and human support, as well as functional intervention, becomes essential to avoid the sense of despair and failure that can lead to regression and prevent rehabilitative progress: the objective must be to channel energies for one's recovery and enhancement - a task that often the person with disability does not feel prepared for - avoiding excess paternalism or emotional

involvement that create victimhood. In this sense, adequate training of rehabilitation therapists to bioethical values should be promoted: In addition to professional competence and continuous scientific updating in collaboration with other health professionals involved to prepare the therapeutic-rehabilitative treatment program of the person with disability, the rehabilitation therapist must be educated to devotion to the other, to the capability of self-sacrifice and solidarity in the conviction of the value of the donation of time and energy even if the results may be uncertain or limited.

The realization, then, of these objectives means to provide - especially in public facilities – appropriate organization of work: the issue of bioethics concerns, then, not only the health personnel but also the institutions in which they work. Indeed, one could argue that the institutions they work for are - somehow - a kind of moral agent that provides the service. This interpretation of the organization as a moral agent moves from the fact that whoever is providing the service can not be seen in an impersonal way: an organization is always the result of the relationship between people who are in it and, therefore, the organization uses these people to accomplish a service.

On the issue of training health care professionals, the National Bioethics Committee has already intervened in 1991 with the document, "Bioethics and education in the health care system", to which we refer for analysis of the theoretical and applicative basis of the dynamics of trainer / formation.

Some professional and human qualities become - in particular - essential to a good relationship between the rehabilitation therapist and the person with disabilities: the ability to comprehend needs, empathic listening that avoids the risks of attachment and the consequent inability to make decisions, the availability to dialogue, recognition of achieved results and the stimulation of therapeutic collaboration; professional autonomy, the ability to work as a team; the intellectual honesty in admitting one's limitations, professional secrecy and respect for privacy, availability of the involvement of family members. It is, therefore, necessary to enhance the capabilities of the person with disabilities and change the perspective of his life: an important example of this approach is the interventions linked to the treatment of paraplegics and tetraplegics in the unipolar spinal unit.

The role of the family of the person with disability is therefore, essential; they can integrate - with the affective and emotional component - the rehabilitation project: the person must feel that others are able to accept him also with disabilities. The not full capacity of extrinsic manifestation of efficiency and autonomy should not compromise in human terms, interpersonal relations; the family remains the main place where the person with disability can mature this awareness, inwardly and gradually. In this sense even the family must not be left alone in this difficult task to which it is often not prepared: the doctor and rehabilitation therapist must constantly communicate with the family, to provide – subject to consent, where possible - the person with disability with information to provide support, in the awareness of the delicacy and preciousness of the contribution in a perspective of co-responsibility. We must focus on the role of the family, in particular, when we consider the minor with disabilities.

Lastly, the role of society is important. The rehabilitation project is completed with the inclusion of the individual in society: it is essential to promote a social

culture that knows how to favourably accept and rethink the value of man beyond psycho-physical incidentals. Inclusion and integration is to be understood at two levels: at the empirical level (by breaking down the architectural barriers, thinking ethically justified any expenditure that knows how to give hope to sufferers) and the human level (by breaking down the barriers and prejudices of the mind). Bureaucratic state intervention is not, therefore sufficient (providing opportunities for care or assistance), but it is absolutely essential to provide a human investment, and a community commitment, so as to avoid forms of loneliness and marginalization, and to look upon the capabilities of each person as richness, preciousness, a human "capital". Even if rehabilitation has costs and does not always pay off (in terms of achieved objectives), even faced with the rehabilitation of severe and unrecoverable disability, proportional intervention, capable of enhancing as far as possible and restoring meaning and hope to a difficult life, always finds justification.

The ethical commitment in the rehabilitation process is divided, therefore, in different levels:

- the person with disability, whose efforts should be supported - if possible - by a desire for the realization of values such as confidence in the future, the ability to make sense of existing capabilities and their lives;
- the doctor and the rehabilitation therapist, who should be able to create a climate of collaboration and trust, which has a decisive role on the rehabilitation process;
- the family, which should be the first social structure involved in the course of action of rehabilitation;
- voluntary work and network of friends, which should give constant support to the family in order to facilitate the increase of the capacity of the person with disability to undertake / resume interpersonal relationships, thus avoiding attitudes of passivity and regression that could be developed by living exclusively in the family environment;
- political institutions, should be aware that proper planning in the allocation of resources can not be separated from assistance to people with disabilities and rehabilitation, even if this requires prolonged intervention with not always positive results, they can not ignore the other problems connected to disability, such as school/education and employment/professional insertion. The ethical commitment of those taking the public decisions, should therefore be, to undertake a social health program aimed at the achievement of "global rehabilitation" which translates into non-discriminatory access to health care, equal opportunities for a person with disability and a person without disability, the proper application of the principle of justice as a response to the needs of the person, the real inclusion in family, social, political, economic and religious life, the promotion of scientific research in rehabilitation, in the accessibility to prosthetic aids.

7. MODELS OF RELATIONSHIP

Rehabilitative medicine includes a variety of a medical, psychological and psycho-social interventions because it is offered to people who may have a wide

variety of disabilities with varying degrees of impairment of their autonomy. This variety of external situations is also reflected in a wide variety of internal situations: from the experience of pain to striving to hope, anger, the desire to get involved, from awareness of unconscious acceptance as in the case of severe mental illness. Also the situations of support may be quite different: from assistance at home to admittance to hospitals or specialized clinics for rehabilitation.

From a bioethical point of view of rehabilitation what emerges - as already stated - is that it must be appropriate and effective for the condition of the person with disability and that it should be implemented in a timely and continuative manner as required. The timeliness of the intervention requires on the one hand, early diagnosis and, on the other, the availability of people, vehicles and facilities, calling into question issues related to the organization of the health system and the availability of financial resources which will be discussed in a later paragraph. However, equally important is scientific expertise and the human "qualities" of doctors and rehabilitation therapists, as well as the collaboration between the doctors and rehabilitation therapists around the person with disability in the conduction of the rehabilitation project: a system of cooperation that must be based on the real-sharing not only of the scientific and ethical aspects, of ethical guidelines and cultural language, but also of the methods and procedures related to evaluation and intervention, and the parameters to test achieved results. The goal is the recovery of the person as a whole, of his autonomy and quality of life: therefore, any "conflict" between rehabilitative methodologies is counterproductive. The choice should be dictated solely by the good of the person with disabilities, the complexity of the situation, and from the peculiarity of the circumstances.

It is also true that, unlike most of the medical or surgical interventions, there is great difficulty in the field of rehabilitation to make a prognosis that has a margin of certainty: it is, in fact, difficult to predict "if" and "to what extent" the person will be able to recover damaged functions and which "collateral cycles" he will be able to activate to compensate for the loss of some abilities. It is for this reason that it is very difficult to determine in advance whether or not it is proportionate to the person with disability to continue a rehabilitation program, if the lack of efficacy is linked to low motivation/participation or, objectively, if there is no possibility of recovery. There may be situations in which it is believed that the time to suspend the rehabilitative intervention: but even when the rehabilitation of an organ or function is not possible, one should never stop "rehabilitating" the person, in order to balance their disability with the acquisition and consolidation of other faculties, keeping him active and creative making the most of his mental, spiritual and moral capabilities. One must always remain open to hope even in the face of limitation, and before rehabilitation idealized as omnipotent, but failed in its overall intent.

To promote the continuity of interventions, taking charge of the whole person, providing hope: in other words, taking "care", becoming a "travelling companion" of the person with disability and - if necessary - of his family.

It is for these reasons that among the possible relationship models, particularly as regards rehabilitation therapist and person with disability, the educational model - which will be discussed later - appears to be the most appropriate. Before analyzing the individual models, we want to clarify that the continuous reference to the rehabilitation therapist is not an attempt to overshadow

the figure of the doctor or doctors who are involved in the rehabilitative process, but rather to highlight that due to the specific roles and continuity in time, it is precisely the rehabilitation therapist that is mostly involved.

There have been identified some models of relationships between rehabilitation therapist and person with disabilities²⁰, among which, the following seem important:

➤ the paternalistic model, which focuses - as is known - on the principle of beneficence and justifies the rehabilitative intervention even in the absence of information and consent of the person with disability. Although appropriate and fully justified in situations where the person with disability is not aware of his state, the paternalistic model loses, however, view of the main purpose of rehabilitation, that is, to restore - if possible - autonomy to the person with disability, whose freedom of choice is constrained by the decision of the rehabilitation therapist and any possible refusal to continue treatment is experienced by the latter as a form of opposition and not as a symptom of a deep discomfort;

➤ the agreement model, which provides for the planning of interventions by the rehabilitation therapist and the person with disabilities with the relative consent of the latter, after the assessment of the risks and benefits. Notwithstanding the absolute centrality of informed consent²¹, it should be noted that the detection of consent may be particularly sensitive and complex in the presence of a mental disability or psychological reactions (fear, anxiety, depression, regression, etc..) when faced with a situation of motor or sensory disability;

➤ the "educational model", looks not only at the technical intervention but to the whole person to help him become aware of his actions and responsibilities, providing adequate and commensurate information and the criteria for evaluation and arousing motivation in the commitment to the rehabilitation process.

According to this interpretation, which seems the most appropriate in a context of rehabilitation, the rehabilitation therapist is not only a technician but also an "educator" in the sense that he must be able to involve the person with disability, providing confidence and serenity. A relationship which - as it is interpersonal - involves the necessity of the ethical dimension, if only for the continuous endeavour of the person with disability and rehabilitation therapist to overcome psychological barriers and personal beliefs, and to compensate for any possible and insurmountable limits, to develop new potentialities of the integral personality.

The individuality of the person with disability has been reaffirmed in the interaction with the rehabilitation therapist, whose significant objective must be to understand and not to direct: each definition of ability should be based on the

²⁰ Cf. also: W. Reich (ed.), *Encyclopedia of Bioethics*, Mac Millan, New York 1995, vol. II (*Rehabilitation Medicine*, pp. 2255-2260).

²¹ Not forgetting the huge amount of literature, the multiple interventions national and international interventions and the documents of the National Bioethics Committee on informed consent, we want to mention here – because it is last in chronological order - the Universal Declaration on Bioethics and Human Rights of UNESCO.

perception that the person with disability has of himself as - again as far as possible – he is the subject of the choices. A partnership, therefore, between the rehabilitation therapist and the person with disability that must be equal and based on doing "together" in a process of mutual enrichment and not on doing "for" someone or "to" someone. A partnership in which, at some point, the rehabilitation therapist should merely have the role of a "travel companion". A collaboration that has as its objective to help the person with disabilities to participate in an authentic way in the outside world and to build a life that is his personal life, open to the future just like that of every other human being.

8. INFORMATION AND CONSENT TO THE REHABILITATION PROCESS

In the educational model "information" is a central element. As concerns the topic of information, the National Bioethics Committee has already intervened - in 1992 - with a document entitled "Information and consent to medical act", in which there are given detailed and clear indications given that may be useful for reflection. It is recommended, in fact, that in case of major diseases and prolonged diagnostic procedures and therapeutic procedures the physician-patient relationship can not be limited to a single, fleeting encounter; the curer must have sufficient skills in psychology to enable the understanding of the personality the patient and his environmental conditions, on the basis of which to adjust his behavior in supplying the information; if the nature of that information can be the cause of particular concerns and suffering to the patient, it must be given with caution, using non-traumatic terminology and always providing evidence to give the hope of one, albeit difficult, chance of success; information about the diagnostic and therapeutic program must be truthful and complete, but limited to those items that the culture and psychological condition of the patient are able to understand and accept, without exasperated details of data (the exact percentages - moreover difficult to define - of complications, mortality, functional failures) that involve the scientific aspects of the treatment. In any case, the patient should be placed in a position to exercise his rights properly, and therefore form a specific will, as regards the advancements and alternatives that are proposed to him; the responsibility to inform the patient lies with the director, in the public health facility, and in any case on whoever has the duty to perform or coordinate."

The first thing to consider is, therefore, information on the damage, on the possibilities of recovery, possible irreversibility: a duty to inform which, in the case of rehabilitation, involves not only the doctor but also the rehabilitation therapist with whom the person with disability and perhaps his family have more direct contact.

Informing means telling the truth about the conditions of the disabled person, on the possibilities of recovery: it is a truth that has specific peculiarities as in all medical practice. In fact, in human relations there can be identified - based on the quality - four types of truth: direct truth as a response to a usually simple question; factual true that refers to an objective reality; personal truth which imparts a more intimate reality (feelings, emotions); interpretative or hermeneutic truth, which is the most complex because the communicator must try to understand the possible

reactions of those listening. The truth to tell the person with disabilities and his family is certainly an interpretative or hermeneutic truth.

It is for this reason that it should be offered only after preparing others to receive it: a truth to be placed within an existential truth, which always knows how to give value to life and also its harsh events, a truth, which must always be open to hope, because not only is it greater than any possible disability but it is also greater than a single person's life; a truth that health professionals are not always able to communicate, unable - often - to help the person with disabilities and his family to withstand the impact of news with a traumatic content; a truth that must be provided gradually, because, especially in the case of the child, no family - no matter how well-functioning - can at the same time deal with news of the disability itself, knowledge of the details related to the specific condition of his family member and the details regarding possible intervention; a truth, that to be communicated requires several interviews in order to understand the specific needs of each person and on this basis to calibrate the possible range of supports and services, a truth that no one ultimately possesses, given the unpredictability of the future and capability of the individual to develop the abilities present.

Information is followed by the obtaining of consent in relation to the capability of the person with disability to take an independent decision; and even when the capacity to make a choice is reduced, assent must - where possible - always be sought. On the other hand, the patient's consent and cooperation are the decisive element of the success of the rehabilitative intervention, and moreover, the great relevance of motivation means that collaboration is always sought and not only in the presence of dangerous and invasive intervention.

In other words, in the rehabilitative process, consent is not an "event" but a "process" in a continuous search for communication and collaboration not only between the person with disabilities and rehabilitation therapist, but also between the various rehabilitation therapists of different expertise should they be present.

The construction of consent is not only a technical and legal moment, but it is morally relevant: it is not enough that the rehabilitation therapist can identify the objective possibility of recovery, functionality and autonomy based on scientifically recognized parameters, but it is necessary that the objectives of the rehabilitation therapist should also be the same as those of the person with disabilities and, if necessary, of the family.

It can, however, happen that there may be no consistency between the objectives of the rehabilitation therapist and the person with disability: there are those who, in the event of this, suggest acceptance of the choice of the person with disability, since - if he is not cooperative - will try to hinder in all ways the rehabilitation process. But perhaps more than passively accepting a partial objective even if shared, the rehabilitation therapist should ask himself why this situation has arisen, and attempt to remove any possible obstacles.

If these objectives are not shared this may also ensue among the rehabilitation therapists who have taken charge of the same person with disabilities: the lack of unity of the team can, without a doubt, affect the success of therapeutic interventions and the serenity of the person with disability, therefore it is fitting to reconstruct a unity of methods, intent and languages in order to have appropriate cooperation for the good of the person taken charge of.

As already said, if in the case of a decision to discontinue rehabilitation interventions one must never renounce "rehabilitation" of the person: often, however, the main problem is not the choice made by the persons involved (rehabilitation therapist or person with disabilities) but rather a shortage of public health resources and the inability of many to make use of private health care. The concept of justice and solidarity, referred to in paragraph 6 of this document must be called into question here.

9. THE CASE OF A MINOR

The birth of a child with disability or the discovery after birth that the child has disabilities "is an event that causes strong maladjustment in every family"²². Each component can react to the situation in different ways over time also in relation to family dynamics and mutual adjustments. In this reflection we focus in particular on the reaction of parents, but we must not neglect the experiences of the brothers of a child with disability²³.

For parents it is often the sudden and painful "awakening" from a dream: the "dreamed" child, the child imagined, that is no longer there; there is the real child with its problems. Parents need to abandon the dream and face the reality; they must fall in love with a child which with its disability, seems to have "disappointed" their plans and desires. The path of acceptance is not easy: it lasts - at times - a lifetime; it is marked by the same emotions that come into play in mourning for a real death; a grief that becomes chronic in the constant comparison with other children, the "mirror" image that reminds of the dream and emphasizes its distance from reality.

How should the news of their child's disability be given to parents? This is the first moment - for the doctor and rehabilitation therapists - when this ethical question is strongly raised. It is the beginning of the story, of the journey: which truth should be told to parents?

Referring to the preceding paragraph in which this aspect has already been analyzed, we want to emphasize that communication of the truth can also affect the second moment of strong emphasis on ethic, that is, the choice of the rehabilitation process. In fact, if there is a delay in making and communicating a diagnosis and in indicating / providing the appropriate supports and services, this may cause serious problems in the subsequent process of rehabilitation of the child. Many parents were disoriented when faced with a discovery that not only created in them so many interrogatives about the future of the child, but also put them in a position of not knowing what to do for it. Consequently, the attention that first focused on the child is moved and focused on its "problem": the child itself became a "problem" in the parents' existence. Each human individual is, however, valued for what he is and not for what he can do and the awareness of being faced, first and foremost, a child, a person, not just a problem, must be a support

²² M.M. Pierro, *Presentazione*, in *Handicap e collasso familiare*, Quaderni di psicoterapia infantile 1994, 29, p. 19.

²³ E. Dall'Aglio, *Handicap e famiglia*. In *Handicap e collasso familiare*, Quaderni di Psicoterapie infantile, 29, Borla, Milan 1994.

to the commitment to "restore to the parents their child as a child and not only as a "problem," the "dreamed" child, even if it has some limitations and to live the recovery processes trusting in hope"²⁴.

A hope that can become real when the parents realize that their child - albeit slowly - begins to respond and that these responses may also depend on the actions of the parents themselves who find how to be useful again to their child. A child must be considered in its totality and in its uniqueness. Globality: because - as said - the recovery goes beyond the physical or psychic disabilities of the child, involving the whole personality; uniqueness: because the hidden potential of the child with disability often exceed expectations.

Hope, however, should be nourished and sustained: this is what is asked by those parents who, day after day, struggle with difficulties, prejudices, and indifference. It is the indifference of others and the consequent sense of loneliness, lack of listening, the modesty of doubt and despair, the having to live every conquest in front of strangers, the fight to assert one's rights, which discourage most parents of children with disability. Promoting the acquaintance of other families with the same experiences or who have already been down the same path is always a great help for those confronted for the first time with a new situation; to prepare the rehabilitation therapists to help parents, aware that there are times when one must stand back and allow the emotional experience of the child and his parents to find its place; to make it clear to teachers that it is important not only to be there but also to be able to maintain a relationship with the child with disabilities in an active and discreet manner. In the name of subsidiarity the good of each person must be sought and supported where it is most needed.

During accompaniment, inevitably, the strain of this journey is experienced: new needs arise, new relationships with the realities that the child faces, time after time. One experiences disappointment when the outside world does not accept the child in its uniqueness and beauty, emphasizing only its limitations. In a society geared to efficiency and success, many parents consider the scholastic performance²⁵ of their child of fundamental importance and to be able to demonstrate that your child has abilities. For the parents of a child with disability, it is a painful situation to go through: they can not enter the "race of pride" with other parents; they are worried that their child growing up can be excluded by peers, and suffer loneliness, not being understood, accepted and loved.

The child must, however, be recognized with its potential and it is always important to keep this in mind so that the perception of limitations does not prevail over the perception of what the child can give. To grow up the child needs to be loved for what he is and not what he should be. Normality for the child is what he

²⁴ M.L. Di Pietro, L. Di Pietro, *"Accompagnare" il bambino con disabilità e i suoi genitori: problematiche bioetiche*, Ospedale Pediatrico Bambino Gesù - Formazione continua in Pediatria, Il Pensiero Scientifico Editore, 2006 (1), pp. 9-12.

²⁵ Without going into the subject of the scholastic integration of persons with disabilities, we will just recall some normative references, including the aforementioned Law No. 104/1992 and Law No. 53/2003 on *the Government Delegation for the definition of the general rules on education and essential levels of performance in education and training* (in the Gazzetta Ufficiale of April 2nd 2003, n. 77).

feels to be; he builds a sense of self based on the image which, in particular, the eyes and expression of the mother's face send back to him.

It is a case, then, of believing in the child, in his strength and his beauty, overcoming two prejudices that prevent a complete vision of reality: that people who can not perform certain activities are inferior to others and that, they are however, not sound of mind. On the other hand, even the way of classifying disability, the listing what is absent, has always been a sign of this prejudice: impairment is expressed as a percentage an indication of the closeness to "normality". To exploit potential means that in order to make the most of what the child with disability has, the enhancing of potential means to give space and provide the tools in order that children with disabilities can express themselves. And, in a society in which the common good is expressed through everyone's good, it is not diversity in the body that should be a cause of concern but - as already mentioned- the reasons why participation in social life is not possible.

It is the responsibility of whoever has taken charge of the child with disability to encourage, develop and to use their potential and to accept the disability. Particular care is needed in childhood and adolescence, when the person with disability begins to be aware of their condition and wonders "why am I not healthy?" No one can give an answer to this question but it is, of course, an invitation to relate to the pain that is manifested, to respect that person, who carries a burden: a burden that can not be eliminated but can be relieved. It is a person who has potential and unexpected qualities, not least a great attention to the things around him and a profound sensitivity: to highlight potential and qualities could be a way of helping them to live with more serenity personal limitations.

In addition to those who accept their own limitations, and collaborate in the rehabilitation process, there may be, however, those who have an oppositional approach: what should be done? Could insisting in the rehabilitative process constitute a sort of "persistent" rehabilitation that does not respect the person? This is a situation which - as previously stated – puts forward a number of ethical questions for which it is hard to find an answer: we should aim towards finding a balance to be created – each time - in respect of the child's personality. This balance may also help to avoid falling into the temptation to "persistently" continue intervention on the child.

The child has potential, but also limitations, neither the one nor the other must prevail. It is important not to give up when faced with limitation but it is also important not to persistent against it: this obstinate persistence arises from the non-acceptance of limit, with the risk that the child is once again thought of as a "problem" and not as a person. We must allow ourselves to be questioned by the limit and try to accept it as an opportunity to look at life differently, in the awareness that the limit has always a greater richness to reveal.

10. SOCIETY AND THE CHOICE OF REHABILITATION

The ethics of rehabilitation should be placed, then, onto a higher and more general level: that of social and health choices. The majority of the more recent reflections recognize that modern society must assume its responsibilities towards

people with disabilities: in fact, the person with disability has particular "needs" to reach a satisfactory standard of the "quality of life" that respects and no longer denies his dignity as a man.

However, still today, there are those who refuse the application of the concept of justice – socially and necessarily - to meet the needs of people with disabilities, as justice is paid by giving to the other of what is his, even if liberality with regard to persons with disabilities is not denied. The negation of the concept of justice is opposed by Nussbaum, who raises three problems - in his view – consequence of the failing to take account of the specific determination of human dignity: the first two concern "the fair treatment of a person with mental or physical disabilities that needs a high amount of care throughout the course of his life"²⁶ and also the support and care towards those "who are independent in certain periods of life and conversely live in a state of deep dependence"²⁷. The third, however, concerns the problem of providing proper consideration of the persons involved in the care practices. Nussbaum claims that we should take account of the "burden on the people who care for those who live in a state of dependency. These people need many things: the recognition that their activity is a form of employment, both human and financial support; the possibility of a profitable and rewarding career and of participating in social and political life"²⁸.

Contrary positions or positions otherwise reserved against the principle of justice are not of course satisfactory for the people with disabilities, who consider it a social duty that there should be real and equal "solidarity" to them.

Apart from any possible extreme positions, it must, however, be recognized that in contemporary society a more widespread "sensitivity" to people with disabilities has been gained. It should, first of all, be cited that the full recognition of their "citizenship" with the affirmation of the equality of fundamental rights of the differently able person as for any other citizen and the faculty or legal right to exercise all rights (with their respective duties) that he is able to exercise. In Italy, the aforementioned Law n.104/1992 is a testimony of the journey undertaken and the achieved legal recognition of full citizenship.

The person with disability has, no doubt, special needs, which an organized society must bear due to the same principle of sociability and reciprocity that should characterize human relationships. Hence the support and assistance (of various kinds from material and psychological to spiritual) that the community can and must make available, to the extent of available resources: for education, training, health and social care and so on, as modulated in the variety of life situations. The same family environment, which can not and neither must be replaced in this primary care, may have its limits (human, technical and economic limits) and must be helped in its tasks with a number of measures. In this sense, the State must intervene with its care facilities or by private initiative or voluntary work, in order to enable a person with disabilities to use all their existing capabilities and collaborate, as possible, to the common interest. Hence, the right to socialization, education and employment, these are also proportional of course to life-situations.

²⁶ Nussbaum, *Giustizia sociale e dignità umana*, p. 32.

²⁷ Ibid.

²⁸ Ibid p. 33.

These principles – be they different in form from State to State - are clarified, or however, derive from constitutional rulings and the same international community espouses them now with documents of a high moral profile and programs focused on practical implementation.

The need to deal with limited economic resources still poses some problems from an organizational point of view, not least the definition of eligibility criteria for rehabilitation in public facilities especially when the demand exceeds the availability in terms of personnel, space and means. We can recall here, by analogy, the *triage* criteria to be met - as is known - the principle of equality and equal dignity, in this case, people with disabilities since everyone has the same personal value and should not be discriminated against.

Referring to the National Bioethics Committee document "Bioethical guidelines for equal access to healthcare" of 2001, it should be noted - here - that no health system can be considered fair if it were to limit itself to making rehabilitation available only to those who are financially solvent.

As concerns the possible criteria for selection they can be summarized as follows in order of importance: 1. need for rehabilitation; 2. urgency as the need to act quickly could affect the outcome of the intervention itself, 3. list, or order of booking. On the other hand, to be rejected as discriminatory, are criteria based on age, geographic area of origin, balance only based on cost / benefit, the most useful in social and employment terms as regards the person with disabilities to be rehabilitated.

In conclusion it must be reiterated, however, that intervention on a social level should always be strongly supported by a culture of favourable acceptance, so it is clear that there are not only changes to the terminology with which to define the condition of disability but that the same terms are given - and not only in terms of positive law - a real content. The words may be, of course, cause and "symptom" of a cultural revolution, but these must be followed by facts: a "signal" that highlights the difficulty of the person with disability, the fear of being abandoned, the 'anguish of those parents who are confronted with the painful thought of "what will happen when we aren't alive" must truly become everyone's problem along with the complete willingness to assume this responsibility.

SUMMARY AND RECOMMENDATIONS

Since the late '70s, the issue of rehabilitation of persons with disabilities has been the subject of careful consideration at both national and international level, with a growing interest also in bioethics. In Italy, Law 833/1978 art. 1 introduces - among the key objectives of the NHS - the issue of rehabilitation. It therefore has been possible to highlight not only the medical aspects of rehabilitation, but also the social aspects, with their reference horizon in the person considered in all his globality and in relation to his living and relational environment. "Foundation" of this approach is a dynamic conception of health: a condition and a lifestyle that must constantly be sought and that also embraces the ethical dimensions, behavior and life choices. The promotion and protection of health becomes a duty

of the individual and society and finds accomplishment in prevention or cure and that can make rehabilitation a technical and cultural tool.

Starting from these considerations and prompted to address the issues of rehabilitation, the NBC has prepared the following document with the intention to present elements of reflection on rehabilitation in general and on the bioethical issues related to it, leaving out - as this is beyond its duties - an analysis of individual clinical situations as well as the description of the multiplicity of rehabilitative interventions available today. The document does not address the complex issue of psychiatric rehabilitation, which the NBC sets aside for possible more specific reflection.

"Rehabilitation" is defined as the set of therapeutic interventions (treatment) and welfare (care) that have as their purpose the recovery (partial or total) of impaired abilities due to congenital or acquired pathologies and the enhancing of existing potential (sensory , motor, psychic) to enable and achieve greater inclusion of the person with disabilities within family and social life. The rehabilitation process is concerned, therefore, in addition to strictly clinical aspects, also with psychological and social aspects. To reach a good level of effectiveness, any rehabilitation project must, therefore, be focused on multiple targets, able to take into account the needs of the person, so that the autonomy that can be reached in different areas may result in the autonomy of the person as a whole and however, in an improvement of the quality of life.

Accordingly, the issue of rehabilitation is presented for bioethical reflection with some unique characteristics that differentiate it from other areas of medicine:

- the necessary and constant reference to a global vision of the person with disabilities, understood in the totality of his being and as such included in a particular social and environmental situation;
- the dilation of time since rehabilitative interventions may last for months or years, thus making the priority a re-reading of the methods of communication and the obtaining of consent and continued involvement - even motivational involvement – of the person with disabilities;
- the multiplication of those involved also including the family of the person with disabilities. And, especially in the case of the child, the family itself becomes a participating collaborator in the rehabilitation process;
- the unpredictability of the results due to the dynamism of rehabilitative interventions and the difficulty of quantifying - in the person with disabilities - existing and hidden potential which can exceed expectations. This requires, among other things, that the proposal of a rehabilitative process moves from a science-based theoretical model by which to establish realistically achievable objectives in the short and long term, appropriate methodologies and tools and methods to verify achieved results. A lax approach could, in fact, lead not only to little or no effective intervention, but also generate the belief that nothing can be done, and reduce the strength of that key factor which is motivated commitment.

Bioethical reflection is, then, called into question at different levels: anthropological level (in determining the meaning of corporality and person); on an ethical level (in identifying reference criteria for rehabilitation professionals directly

involved in the determining and implementation of the rehabilitation program, and for the person with disabilities, whose autonomy may however be limited or conditioned), at the legal level (in identifying the person with disabilities as a subject with rights) at the social-political level (in planning and allocating resources to invest in rehabilitation and the planning of intervention directed at the inclusion of the person in the community).

Starting from the analysis completed at these levels, the NBC has made the following observations and recommendations.

1. The *ethos* of the experience of disability is the body, not as an "object" perceived in its mere physicality, but rather as a corporality that is "lived" as "body", an expression of human subjectivity of the bodily dimension as constitutive to the identity of the person. As the experience of a personal body, disability does not only concern physicality or only the psyche, but both of these dimensions. Disability becomes experience and perspective of limitation in the knowledge that it is a constitutive and objective part of human life: in this sense, the limitation may be the opportunity to rethink one's potential and the disability should be seen not as an expression of what is absent but as a means to enhance what is possessed. It is precisely starting from these considerations that we have witnessed an evolution in the concept of "handicap", not only a semantic evolution but an evolution in both content and anthropological foundations, also evident in the documents approved by the World Health Organization and United Nations. These changes have brought about, firstly, the bringing of attention to the different abilities rather than disabilities, assessing them – therefore – as capabilities and *performance*. The aim of rehabilitation should therefore be to ensure the full participation of every person in social and relational life, trying to break down every barrier that prevents full enhancement and social inclusion, i.e. participation in decision making and programmers of the entire community.

2. As a response to the "needs" of the disabled person, an "integral" ethical approach is deemed the most appropriate, which takes into account the totality of the subject to be rehabilitated, and - shifting the barycentre of the reflection from appearing to being - recognizes man's value regardless of the functions that he is able to carry out . In light of the integral approach, rehabilitation involves different levels (physical, psychological, ethical and spiritual) and presents itself as a dynamic project, always able to adjust to the objective situation and that to be accomplished must move from its being shared by all the subjects involved in a sort of enlarged "rehabilitative" alliance grounded in constant dialogue and mutual cooperation. On the other hand, rehabilitation, is not undergone passively, but rather to carried out as active interaction, giving rise to inner motivation and personal commitment to recovery, evoking all existing potential and mobilizing inner energies and for the full development of the self. To this end, the NBC considers it essential to operate in two directions: to promote appropriate training of health personnel - and, in particular, rehabilitation therapists – to bioethical values, and firstly, to the dedication to the other, the ability of solidarity, empathy, in fostering the development of a social culture centered on favourable acceptance and inclusion and who knows how to rethink the value of man beyond that of

psycho-physical incidentals. At the empirical level, it involves the removal of architectural barriers and ethically justifies every expense, able to give back hope to those suffering; on the human level it is necessary to break down the barriers of the mind and common prejudices.

3. The rehabilitation process, as described, may be carried out within a relational model of an "educational" type, which looks not only at technical intervention but to the whole person to help him acquire – as far as possible - an awareness of his actions and his own responsibility, by providing appropriate and proportionate information, evaluation criteria and arousing motivation as regards commitment. In the context of this report, the aim of those engaged in rehabilitation must be to understand and not to direct, in order to build collaboration focused on "working together". For this reason, a special role is played by the phase of information and detection of consent to the rehabilitative process. By reference to the Document "Information and consent to medical treatment" (1992), the NBC reiterates the essential and required elements of informed consent in the context of rehabilitation as a form of safeguard of the ethical dimension of the relationship. In particular, it is recommended that special attention should be given to the content of the information (to damage, the likelihood of recovery, possible irreversibility) the recipients of the information (person with disability and family), taking care – to communicate a truth that is in its same nature interpretative or hermeneutic - to predict and understand the possible reactions of those listening. A truth that must be global, open to hope, and gradual, and which is to be communicated within a "process" of accompaniment in which there is the ongoing search for consensus in terms of mutual cooperation, and first and foremost, the identification of common objectives.

4. Strong support should be given to the families that have a person with severe disabilities and, in particular, a child with disabilities. In this case, it should be noted how the news of their child's disability may require an additional emotional input from parents and the son in them feelings of anxiety and distress "from abandonment" on the part of society. Alongside the need to ensure each family only a short time for diagnosis and the start of rehabilitation intervention, it should be stressed how fundamental it is to secure the active participation of the family in the rehabilitation process, in order to find further help to elaborate the loss of the "dreamed" child and to feel useful for the "real" child. The realization of this project has to start from looking at the globality and uniqueness of the child: globality, because the recovery goes beyond the physical or psychic situation of the child with disability, and involves the whole personality; uniqueness, because the hidden potential of children with disabilities greatly exceeds expectations. From this perspective, it is essential that those engaged in the rehabilitation take an ethical stance inclined to: supporting and encouraging the parents' hope; capable of listening; fostering solidarity among families who live through the same experience or who have undertaken the same journey; forming oneself on the ethical and humane level to know how to establish a genuine relationship of assistance to families; including through promoting subsidiarity even through public support measures. The objective to be reached must be the enhancement of the potential that the child with disabilities has, giving space and offering the

tools for its expression. Therefore, it is the task of whoever accompanies children with disabilities to encourage them to develop and use their potential and accept their disability, helping them to live serenely with their limitation.

5. The acceptance of limitation is a bioethical problem which concerns not only the child with disability but also the adult with disability, as well as those involved in rehabilitation. Particularly delicate is the situation where the person with disability develops oppositional dynamics and refuses to cooperate in the rehabilitative process. In this case, there might be the doubt that the insistence on rehabilitation could constitute a sort of aggressive "rehabilitation", for this assessment the criterion of proportionality is not enough if it is not included in the search for equilibrium to be created each time in accordance with the personality of the person with disability. The search for balance, consequently leads to being confronted with existing potential but also with the limit: and if one should not give up when faced with limit, neither must one relentlessly persist against it. Aggressive "rehabilitation" arises exactly from non-acceptance of limits and carries with it the risk of starting to think again of the person with disability not as a person but as a "problem".

6. The ethics of rehabilitation should be placed, then, on a more general level: that of political and health choices. This area of reflection must move from awareness of the special needs of persons with disabilities, to which modern society has to undertake very specific duties. In particular, the principles and objectives that should guide policy and health choices must be: the principle of sociability and reciprocity in human relationships, support and assistance that the community should make accessible in proportion to available resources, the intervention of the State with its care facilities; the principle of subsidiarity, with the promotion of private initiatives and voluntary work; the protection of the right to socialization, schooling and employment; the principle of equality, of equal dignity and equal access to rehabilitation of persons with disabilities in public and private facilities. In particular, the criteria for selecting patients for access to rehabilitation, in the presence of demand exceeding supply of services, can be schematized according to a hierarchical order: the need for rehabilitation, urgency, since not intervening in a timely manner could jeopardize the outcome of the intervention; the list, or order of booking.

Based on these premises, the NBC puts forward some indications of bioethical commitment:

- the right to rehabilitation of the person with disability should always be recognized and strongly supported as part of the essential respect for the equal dignity of all human beings;

- society should undertake, both culturally and economically, to provide assistance to persons with disabilities and those who are not self-sufficient even if the rehabilitation should require lengthy intervention and give not always positive results, and it should not ignore the other problems related to disability, such as inclusion in school / education and employment / professions;

➤ there should be adequate attention - within university courses - to the comprehensive formation of health workers involved in rehabilitation, so as to offer them not only technical and scientific skills but also sensitivity to the human problems of the person suffering and the ability to understand the ethical and social responsibilities involved in the action of curing;

➤ there should be - especially in public facilities - a proper organization of work, because the bioethical issue involves not only the health personnel but also the institutions in which they work;

➤ there should be strong support given to associations and voluntary work involved in the care of persons with disabilities and assistance to families.

➤ the development of a culture of rehabilitation should be encouraged, so that it becomes clear that the difficulty of the person with disability, the fear of being abandoned, the anguish of those parents who are confronted with the painful thought of "what will happen when we aren't alive", must truly become everyone's problem along with the complete willingness to assume this responsibility.