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## Italian Legislative Framework and Policies of Disability

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**Abstract:** The most important reference in Italian legislation concerning interventions in favour of people with disabilities came about with Law 104 from February 5th 1992 in which the most important rights for disabled people were established. This law led to a new vision, the person with disabilities is no longer seen only a subject needing help but as a person who has the right to live his life in the best possible way that his condition allows him to and thus, it is society's duty and that of the Government, to do everything possible to remove invalidating causes, to promote a disabled person's autonomy and to realise his best social integration possible. To implement what is foreseen by this law it was necessary to activate different important interventions, two of which are very significant: the realisation of Guidelines from the Ministry of Health on rehabilitation activities in which the aims are defined on how rehabilitation should be implemented and how it should be organised on a national level and at a community level. Law 68 from March 12th 1999 decreed the full rights of people with disability to be integrated into the workplace. In the article we will also report some significant data concerning the results of the applications of the law.

**Key words:** new vision; charity; welfare; rights; autonomy; social integration; rehabilitation guidelines; right to work

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To describe the Italian system of Government interventions in favour of people with disabilities, three normative regulations need to be referred to which, during the nineties (from 1992 to 1999), signalled a sharp change in the interpretation of assistance.

These were:

1. Law 104 from 1992 "Law-framework for the assistance, social integration and rights of the disabled".
2. the "Rehabilitation guidelines" published in 1998
3. Law 68 from 1999: "Norms for the right to work for the disabled".

At the base is the principal that people with disabilities need to be regarded with the aim of identifying the most efficient ways of removing any obstacles that could prevent them from developing all their potential to help them reach their highest possible level of autonomy and social integration, providing them with rehabilitation therapy and the necessary aids to make this possible.

Early and timely intervention—from the first moment of diagnosis or from a clinical point of view clinically potentially disabling—avoiding the potential worsening of the disability—both

physical and psychological; the supply of suitable aids permits better management of difficulties or incapacities, rendering assistance less difficult and allowing in many cases a good level of autonomy. All this reduces the subsequent care burden favouring at the same time promotion of the individual and the reduction of global costs.

Important scientific research is consequently developed which leads to remarkable growth in rehabilitation science which makes the Individual Rehabilitation Project the central nucleus of any intervention. A team of professionals: doctor, therapist, psychologist, social worker and any other "expert" necessary to respond to the specific needs of the disabled person, evaluates his potential and establishes — sharing with him and/or with his family — the intervention plan: physiotherapy, rehabilitation, speech therapy, aids, which can be provided bearing obviously in mind the resources made available through the health and social services system.

A single operative unit permits system interventions which are synergic and never contradictory. A single unit is easier to man-

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age and to control, also regarding costs; it defines treatment plans and intervention plans as well as the aid programme necessary for each person, ensuring through its competence that the person is provided with what he really requires and is thus also responsible for the results of any interventions. For more complex aids, those that require precise adjustment to the characteristics of the person, aptness and follow up is ensured and the disabled person is not left alone to make choices which he certainly does not have the competence to make. What wheelchair is the most suitable for him? How does a posture system to prevent spine deformities and allow most freedom to the upper limbs need to be adjusted? What is the most efficient position for the self-pushing wheels of a wheelchair in the case of a person with upper spine injury? Is that person with that disability able to drive a car? And with what special devices and making use of what remaining capabilities? These are questions that a disabled person cannot easily answer by himself.

And also for less complex aids expert supervision is often necessary: are there people in this family who are able to use a lift for the disabled? What antidecubitus cushion is the most suitable for that level of risk? Finally, cost monitoring becomes easier if the person who decides what to provide is an employee of the national health system.

An excursus into the "framework" of basic regulations in our care system will allow us to understand the reason behind certain choices, how we are putting them into practice and to evaluate the analysis of the first results.

#### **1 Law 104 of 1992: a revolution in the concept of assistance for the disabled**

For a long time in Italy the awareness has existed that people with disabilities have inalienable rights and also that it is the duty of a civil country to provide disabled people with the care, aids and services that can allow them, all of them, to reach the highest level of autonomy possible.

From the beginning of the 1980's disabled people have been supplied with wheelchairs and other aids to facilitate their assistance and numerous laws decreed the right of people with disabilities to adequate rehabilitation care and to the necessary aids.

The law though that signalled an important crossroads in the assistance of people with disabilities was **Law 104 of February 5th 1992**.

This law brought about a new outlook: a person with disabilities is no longer seen only as a person needing care and assistance but as a person who has a right to his life and therefore everything possible must be done to remove disabling causes, to promote the person's autonomy and to ensure the best possible social integration.

At the beginning of the nineties medical, psychological and scientific discoveries caused major cultural changes.

At the end of 1986 Rita Levi Montalcini, together with Stanley Cohen, were awarded the Nobel prize for medicine for discovering neuron growth factors (NGF, a polypeptide that plays a fundamental role in growth and in the differentiation of particular cells and nerve fibres) and the interest in this event contributed to the rise in the conviction that some disabling pathologies such as for example in the cases of stroke, survivors can be cured and the disability recovered.

Studies linked to the psychology and formation of personality show how the environment, the context, one's own expectations and those of others have a significant influence in changing an individual's attitude. If others think that you will always be disabled and you will always need care, probably the will in you to use your remaining potential to the full won't grow and you will remain closed in your impotent shell.

**Science and technology beyond unimaginable frontiers** and incredible aids are produced to help people walk; extra-light and electronic wheelchairs that even a person with severe disabilities can manage by himself; from a very early age children can be seated so that they can participate in family life, they are stood up and helped to walk. Stairs are no longer a problem and aids that are ever more simple to install and nicer to see are proposed.

All this brings about a deep cultural change: it goes therefore from the appraisal not of what a disabled person doesn't have or has lost but to the appraisal of what a disabled person has, of his potential and the question is: what can be done to develop this potential? Are there any aids that can improve his autonomy? What could the person who doesn't walk do if he had them???

The Italian Government, urged by associations for the disabled and by the scientific community of rehabilitation doctors assimilated this change and issued, in 1992, a "law framework", Law 104 "for the assistance, social integration and rights of handicapped people", a law that established the reference for all subsequent policies in favour of disabled people.

In these last few years, Law 104 has been updated many times; the last update was in 2010 (183).

The aims of Law 104 are essentially two:

a) guarantee full respect for human dignity and the rights of a handicapped person to freedom and autonomy and promote full integration within the family, at school, at work and in society; avoid and remove disabling conditions that prevent a person's development, the reaching of the maximum autonomy possible and participation of a disabled person in community life.....

b) pursue functional and social recovery of a person affected by physical, psychical and sensorial disabilities and assure services for the prevention, cure and rehabilitation of impairment.....;

With Law 104, the Italian Republic pledges, among other things, to carry out all the interventions to:

— develop scientific, genetic, biomedical, psychoeducational, social and technological research also through target-oriented programmes agreed with public and private institutions;

— assure prevention, diagnosis, prenatal and premature therapy of disabilities and the systematic research into their causes;

— guarantee timely intervention of therapeutic and rehabilitative services that assure the recovery allowed by scientific knowledge and by the techniques presently available, maintenance of the disabled person within the family and social environment, the person's integration and participation in society;

— assure primary and secondary prevention in all phases of growth and development of a child and a disabled child to avoid or quickly ascertain the onset of a handicap or to reduce and overcome the damage of a further handicap;

— assure the supply and repair of equipment, prosthetic devices and technical aids necessary for the treatment of disabilities

and to avoid handicaps.

Law 104 also defines:

— the right to education and training right from a very early age.

— a handicapped child aged between 0 and 3 years is guaranteed a place in day nurseries. The right of a disabled person to education and to training at nursery school, in common classes in all types and level of school and at university. School integration has the aim of developing the potential of a handicapped person with regards to learning, communication, relations and to socialising.

— the right to professional training and to integration in the workplace.

— the compulsory elimination or overcoming of architectural barriers in all public or private buildings open to the public.

#### **What has changed in Italy with Law 104.**

The most important change has come about in the mind of disabled people and of their families. What until now had been a desire, an aspiration: to go to school, to work, to enter shops, public offices, theatres; to go out alone, has now become a right as it is a right to receive equipment, prosthetic devices and the technical aids necessary for the treatment of disabilities and to avoid handicaps for free.

As it is a law outline, Law 104 obliges legislators to adapt all existing provisions to the principles and to the new dispositions contained within it, completing the norms with new legislative instruments necessary for its full accordance.

It is not an easy task and it poses complex problems such as:

— The reorganisation of existing rehabilitation and care structures and the realisation of new suitable community care rehabilitation centres<sup>1</sup>.

— The creation of appropriate ways of evaluating the effective potential of each person with disabilities with the aim of integration at school and at work;

— The restructure of all public buildings (first of all schools and health and administrative centres) with the removal of all architectural barriers and the creation of health services with no barriers to allow access to people with motor disabilities;

— Regulation of assistance regarding prosthetic devices and aids: what devices to supply, to whom, in what way, following what evaluation and to reach what objectives.....;

#### **Rehabilitation at the centre of intervention choices.**

The bottom choice of the Italian Government that characterises all policies and subsequent actions places rehabilitation at the centre of every intervention in favour of a disabled person: it is the rehabilitation team, made up of different professional figures according to the type of disability and guided by a rehabilitation doctor who defines, for each person, the goals that can be reached, the treatment required, the aids that will be necessary to reach the identified goals.

The putting into action of Law 104 therefore imposes as the first thing the creation of "Guidelines for rehabilitation activities".

#### **2 Health Ministry guidelines for rehabilitation activities: goals, procedures**

In October 1994 the Health Ministry commissioned the Italian Scientific Association of Rehabilitation Medicine the project of national reorganisation of rehabilitation medicine. Among the sev-

en experts who worked on this project was Prof. Alessandro Giustini, co-author of this article.

The **Health Ministry guidelines for rehabilitation activities** were published in 1998 and represent the "concrete" translation of the spirit of Law 104. They indicate how the goals of autonomy and social participation indicated by the law as rights for disabled people and therefore as duties for society are to be reached.

<sup>1</sup>See article: Rehabilitation guidelines: community care structures

Until the nineties, for Italian culture "taking care of a person" meant helping and assisting him/her; after Law 104 a new vision came into our common thought, a vision that said: taking care means to ensure that people are offered all the possibilities so that they can, as much as possible, do things by themselves: rehabilitation is important so that each person with disabilities has the least possible need of assistance and has all the help: treatment, exercises, aids so that they can do all they are able to by themselves.

#### **2.1 Rehabilitation: social field or health field?**

For a long time it has been debated whether interventions in favour of people with disabilities should be placed in the health field (Ministry of Health) or the social field (Ministry of Social Affairs).

The answer of the experts is found in the first part of the "Guidelines"

".....The assistance of disabled people can be placed in neither a purely social nor in a purely health field: it is essential that sociomedical interventions are carried out through an integrated sociomedical plan which implicates a strong link between health intervention programmes, aimed at developing all the potential resources of an individual with social interventions aimed at making resources and environmental potential available and thus to extend and strengthen rehabilitation intervention, allowing the integration or the reintegration of the disabled person in the different cycles of social life and the improvement in the persons' survival and quality of life.

Under such a context come also the answers to "lifelong protection" of people who are completely non self-sufficient or who have minimal responsiveness. Such types of disability and handicap pose new problems and they are progressively rising as has emerged from the most recent epidemiological data relative to serious disabilities such as those deriving from the outcome of serious brain damage like encephalitis, states of coma, vascular malformations, complete medullary cervical injury, ischemic cardiopathy, cardiac decompensation, respiratory insufficiency, etc.

#### **2.2 Rehabilitative interventions: aims and stages**

Rehabilitative interventions are oriented towards four objectives:

— the recovery of functional competence that has, for pathological reasons, been lost;

— the developing of a competence that didn't appear during growth;

— the need to reduce and control functional regression trying to modify the natural history of chronic/degenerative illnesses by reducing the risk factors and dominating progression;

— the possibility of finding facilitating alternative formulas.

Rehabilitation intervention begins at the same moment as the damage starts. The term is defined by an accurate balance between

stabilisation of the results and the presence of recovery potential.

— The first stage of rehabilitation starts chronologically at the same moment in which the disability occurs and, thus, either in the acute phase of the illness or at the finding of a congenital or chronic pathology.

— The start of the second stage of rehabilitation is based on the remaining disability as soon as the acute phase of the illness has passed; this concerns the post-acute phase and regards both hospital structures as well as external rehabilitation centres, independent from their legal status (public or private).

— The third stage requires less systematic health interventions (as pertaining to a stabilised handicap condition) and thus can be carried out also as an out-patient, aimed at maintaining functional autonomy achieved by the patient and at the prevention of possible further regression.

The above-mentioned criteria are valid, in general, for any age and for any disabling pathology or potentially disabling pathology. Childhood and old age as well as psychic pathologies require specific consideration.

Therefore.....

Rehabilitation must develop the potential (even the minimal) that every person has. The person has had an accident and the spinal cord damage has left him a paraplegic? Let's evaluate what the highest degree of autonomy is that he can reach and we'll construct a plan that will teach him to have a bath by himself, to dress himself, to cook, to drive a car..... We'll give him a light wheelchair that he can load by himself into his car. We'll choose the most suitable wheelchair for him, perfectly suited to his body, adapting the position of the wheels and the footrests so that it takes the least effort to drive it. If the damage is more severe and he can't push the wheelchair by himself, we'll choose an electronic wheelchair with easier controls, the posture system that will facilitate his transfers and provide him with the most comfort and stability. If a person is completely immobile and can only control eye movement, he must be equipped with a communication system that reads the movements of his pupils and translates them into words.....

When should this be done? Immediately, as soon as possible. The person must think at once that he has possibilities; he mustn't receive the message that "all is lost", that he will no longer be able to do anything.....

We need the will of the person to construct, together with him, his new future.

### 2.3 Child Rehabilitation

This must also take place with children: as soon as it is understood that something is not right with their development all ways must be investigated to help them participate in family life and in that of other children. Systems to have them sit up that don't worsen their postural behaviour must be found; that allow them to be at the table with their family or at a table with their friends; that have them stand up quickly so they perceive their vertical position; that suitably support them to help them walk. We cannot leave them to grow up thinking they are incapable and useless and postpone assessment of their capabilities to when their personality is already formed. The progress of science teaches us that personality is built step by step and a person who has never been offered stimuli becomes apathetic and psychologically dependent: unable to desire

(and therefore to gain) autonomy.

It is about making an investment at the beginning to get something back later: people who we make autonomous notwithstanding their disability will be less dependent, less in need of assistance and will be able to become active members of society.

### 2.4 Rehabilitation activities taking in global charge

Any activity aimed at improving the autonomy and participation of a disabled person can be defined as being rehabilitative. This must be part of a path of rehabilitation precisely planned for each person and organised with regards to the goals to be reached.

".....health rehabilitation activities" are defined as assessment, diagnostic, therapeutic and other intervention procedures aimed at containing or minimising a person's disabilities and helping them to effectively move, walk, speak, dress themselves, eat, communicate and relate well in family, work, school and social environments—"social rehabilitation activities" are defined as actions and interventions aimed at guaranteeing a disabled person the most participation possible in social life with the least restrictions possible independent from the gravity of the disability or from irreversible disability, in order to contain the disabled condition....."

Rehabilitation activities, with the exception of those of simple instrumental physical therapy for minimal, segmentary and/or temporary disabilities, necessarily require the global clinical taking in charge of the patient through the availability of an individual rehabilitation project and its realisation through one or more rehabilitation programmes.

#### Rehabilitative project

The individual rehabilitative project is elaborated by the rehabilitation team, coordinated by the doctor in charge.

The individual rehabilitative project:

— Takes globally into account the needs, preferences of the patient (and/or of his family, when necessary), his disabilities and, especially, his remaining and recoverable abilities, besides other environmental, contextual and personal factors;

— Defines the desired results, the expectations and the priorities of the patient, of his family, when necessary, and of the care team;

— Must show awareness and comprehension, on the part of the whole rehabilitation team, of all the patient's problems, including any aspects that are not subject to specific intervention;

— Defines the role of the rehabilitation team, made up of expertly trained personnel, with regards to the actions to be undertaken to reach the desired results;

— Defines, in general outlines, the short term, mid-term and long term aims, the foreseen timescale, the actions and conditions necessary to reach the desired results;

— Is communicated in a comprehensible and appropriate way to the patient and to his family;

— Is communicated to all the operators involved in the project;

— Constitutes the reference for any intervention carried out by the rehabilitation team.

The coordinating doctor on the rehabilitation team, in agreement with the same team, takes steps to guarantee a constant flow of information from and with the family doctor, and with all the structures involved in the rehabilitation plan.

The individual rehabilitative project must be modified, adapted and newly communicated to the patient and to the operators if there is a substantial change in the elements for which it has been elaborated (needs, preferences, disability, remaining ability-disability, environmental and resource limits, expectations, priorities) also with regards to timescales or previously defined actions or conditions.

### Rehabilitation programme

The rehabilitation programme is put into practice through specific programmes.

The choice of the aids necessary to reach the aims defined by the rehabilitative project, adjustment of the aid to fit the person and training in the use of the same, even for normal use, constitutes one of the most important programmes of the working project.

For example, for a person who has had spinal injury and has been left paraplegic, the aid personalisation programme to allow an autonomous life and the learning of how to use aids correctly constitutes the central part of the rehabilitative project.

The choice of wheelchair, the adjustment to make it perfectly suitable to the patient's capabilities to allow the utmost efficiency in pushing using the least effort, the choice of the most appropriate anti-decubitus cushion and mattress, adaptation of the bathroom and the kitchen up to driving lessons in cars with special controls may require up to a few weeks and the intervention of a wide range of competent experts and professionals.

The right choice and training will allow, in most cases, recovery of full autonomy.

For children the aids programme is always very delicate and complex. Usually it is almost impossible to predefine the type of aid and the duration of its use as it is fundamental to be able to adapt the aid to the morphological growth of the child, as well as to the child's changing abilities. An aid that has not been dimensionally adapted to the morphology and growth of a child can cause the onset and fixing of pathological and deformity postural behaviour.

### 2.5 Importance of assessment

In every case, the moment of assessment and definition of goals is a crucial moment: it is a moment that requires specific competence, not easily delegated to only one person but in almost all cases it calls for the collaboration of different fields and professionals. It is the moment when it is established what can be done, what can the disabled person become.

The goals to be reached cannot be underestimated, but nor can they be overestimated: not to reach them could lead to depression, to frustration.....

Thus the composition of the team that has to assess and prepare the rehabilitative project is extremely important. Very often the efficiency of interventions derives from the appropriateness of the team.

## 3 Health Ministry rehabilitation guidelines

### Rehabilitation interventions and articulation of healthcare providing centres

Rehabilitation intervention begins the same moment as the damage starts and can be considered as concluded when the situation can be considered stabilised and the maintenance and/or prevention phase of disability progression begins.

The rehabilitation path, unique to each person and defined in the specific Individual Rehabilitative Project, is divided into different phases based on the modifiable margins of the general outline of the disability, on the degree of clinical stability and on the presence of recovery potential and modifiable elements in the person's general situation.

### 3.1 Rehabilitative intervention phases

The rehabilitative intervention phases can be thus described:

— **Prevention phase** of secondary damage and of consequent disablement in an acute phase: the assessment and rehabilitative intervention must always be started right at the beginning of the potentially disabling event;

— **Intensive rehabilitation phase**: assessment and intensive therapeutic interventions linked to immediate post-acuity of the illness when a rehabilitative intervention can positively influence the biological processes that aid recovery, containing and reducing the entity of the disablement and when the disability is more modifiable;

— **Completion of recovery process phase** and of the rehabilitation project (extensive or intermediate rehabilitation).

— **Maintenance and/or prevention of disability progression phase**: characterised by different types of rehabilitative health interventions usually integrated with social rehabilitation activities.

### 3.2 Types of rehabilitation interventions

In relation to the intensity and complexity of the health rehabilitation activities and to the quantity and quality of the resources absorbed by the same they are distinguished in:

**Extensive or intermediate rehabilitation activities**: therapeutic rehabilitative activities from one to three hours daily and good care support intervention, directed at:

— temporary and/or minimal disability requiring a short and simple therapeutic-rehabilitative programme that can be carried out as an outpatient;

— serious disability with possible permanent results requiring long term care.

Treatment times are usually kept to within 240 days, except for:

— patients affected by serious pathologies of an involutional character (multiple sclerosis, muscular dystrophy, amyotrophic lateral sclerosis, Alzheimer's disease, some congenital pathologies with a genetic base), with serious brain damage or psychic disturbances and the multi and sensorial disabled, for whom the rehabilitative project can also be extended further with no limitations;

— patients "stabilised" in their condition of imperfect functional recovery for whom periodical cycles or rehabilitation are foreseen (on an annual base for example);

**Intensive rehabilitation activities**: aimed at the recovery of serious, modifiable disabilities that require highly specialised medical diagnosis of a rehabilitation or therapeutical nature in terms of complexity and/or duration of intervention (at least three hours daily of specific therapy provided directly by rehabilitation health technicians: physiotherapist, speech therapist, occupational therapist etc.).

Treatment times are usually kept to within 120 hours: intensive rehabilitation is directed at:

— complex pathologies requiring stay in a specialist rehabili-



tation unit;

- more serious and more complex disabilities.

### 3.3 Organisational levels

In general rehabilitation is provided through a network of hospital and outpatient structures. This can be:

- continual hospitalisation and/or daytime;
- continual residential care and/or daytime;
- outpatient surgery and home care.

**3.3.1 Extensive or intermediate** rehabilitation (therapeutic rehabilitation from one to three hours daily with good care support) are provided at long-stay hospitals, community outpatient functional recovery and re-education surgeries and hospitals, outpatient rehabilitation centres, healthcare homes, home care ;

The supply of necessary aids for extensive and intermediate rehabilitation is guaranteed, also at home.

**3.3.2 Intensive** rehabilitation is provided in wards called Operative Functional Recovery and Rehabilitation Units in hospital structures—multi or monospecialist—where recovery and high intensity diagnostic care and assistance is already present and is aimed at those that require specialist medical rehabilitation care and highly specialised 24 hour nursing or daytime nursing, not provided in day hospitals with recoverable disability where treatment cannot be deferred.

In particular, assessment and intensive therapy (at least three hours of treatment per day) can be carried out under ordinary hospitalisation or in day hospital.

Intensive rehabilitation and specialist orientation can also be foreseen within the community care programme, which needs, for its characteristics, specific organisation, in particular dedicated to:

- **Cardiological rehabilitation** which has the task of putting into practice all the required interventions to guarantee the best physical, psychological and social conditions so that chronic or post-acute cardiovascular patients can keep or take up their places in society again;

- **Respiratory rehabilitation** has the task of putting into action all interventions directed at patients and the families of patients with pulmonary disease, usually by an interdisciplinary team of specialists, with the aim of making them reach and maintain the maximum.

Within the community care programme, Highly Specialised Intensive Rehabilitation Units can also be finally foreseen, such as:

- **Unipolar Spinal Unit**
- **Unit for serious acquired brain damage and serious brain trauma**
- **Unit for serious disability in children**

#### 3.3.2.1 Unipolar spinal unit

The Unipolar Spinal Unit (USU) is aimed at assistance for people with spinal damage, of a traumatic origin and non, from the moment of injury and has the goal of allowing myelosis patients to reach the best state of health and the highest level of functional capability compatible with the injury.

From an organisational point of view, the Spinal Unit is located inside hospitals with second level DEA—Department of (highly specialised) Accident and Emergency—and makes organised use of, besides the specialities already foreseen by DEA, also of the following specialist activities: urology and urodynamics, plastic

surgery, physical and rehabilitation medicine, clinical psychology, gynaecology, andrology, clinical nutrition, neurophysiopathology, pneumology, image diagnosis, including CT and MR scans.

The spinal Unit constitutes an autonomous operative unit and uses the professional, instrumental and building resources present within the structure it is located in through an interdisciplinary (departmental) organisation which satisfies the different clinical, therapeutic-rehabilitative, psycho-social necessities of the patients affected by spinal injury, suspected or confirmed, through normal hospitalisation, day hospital and outpatient surgery, making use of full-time medical personnel and programmed access, in order to guarantee unity of intervention and a multi-discipline approach, both in the early phases and in the rehabilitation phases.

The Unipolar Spinal Unit:

- acts to accept patients within the first hours of the trauma providing them with appropriate assistance and full treatment;

- takes charge of the patient with suspected or confirmed spinal injury and the patient who requests to be taken charge of for diagnosis and/or therapeutic interventions subsequent to the first hospitalisation. For each single patient a personalised rehabilitative project must be programmed and put into action. The duration of any hospitalisation period in the functional emergency area must be as short as possible as the aim is for an early transfer to the spinal Unit's own hospital beds and sub-intensive therapy.

The Unipolar Spinal Unit is characterised by assessment and rehabilitation aimed also at cooperation with the Centres of information and documentation of aids regarding the setting up and updating of data banks aimed at direct information to the operators and to disabled people with particular reference to the problems of paraplegia and tetraplegia.

#### 3.3.2.2 Unit for serious acquired brain damage and serious brain trauma

The Unit for serious acquired brain damage and serious brain trauma is aimed at the taking into care of patients affected by serious acquired brain damage (of traumatic origin or other nature) and/or characterised in the clinical evolution by a period of coma more or less protracted and by the coexistence of serious behavioural disabilities which determine complex and multiple disability and which need assessment and therapeutic interventions that cannot be carried out at other healthcare structures that provide intensive rehabilitation.

**<sup>3</sup>D. E. A. 2<sup>nd</sup> level** it is the Departments of Accident and Emergency that assure, besides services provided by DEA 1st level, more highly specialised functions linked to emergencies, among which cardiac surgery, neurosurgery, neonatal intensive therapy, vascular surgery, thoracic surgery.

This is located at the heart of hospital structures which have 2nd level DEA (see note 3) and must be strictly linked with the emergency Services in order to:

- guarantee timely reception of the patient with brain injury;
- provide own consultation immediately after the trauma and during the phases of intensive care and/or neurosurgery;
- collaborate in the education and training of the relative personnel;
- participate in common therapeutic protocols.

This must be activated in a hospital where the following spe-

cialist departments are present and available: intensive care and intensive therapy, neurosurgery, functional recovery and rehabilitation, neurology, otolaryngology, ophthalmology, general surgery, general medicine, endocrinology, maxilla-facial surgery, clinical psychology, orthopaedics and traumatology.

Essential components of the unit for serious acquired brain damage and serious brain trauma is the state-of-the-art sub-intensive area for functional recovery and rehabilitation able to guarantee, besides intensive internist assistance, more structured and continuous rehabilitation, as well as daily contact between the patient and his family. The passage into this area, linked to intensive care and equipped with a specific organisation of the work spaces, comes about as soon as the problems related to the guarantee of the patient's survival have been overcome and an initial and partial autonomy from the respiratory assistance system is possible.

The unit for serious acquired brain damage and serious brain trauma must guarantee the family appropriate formalised information and training also for the people who will be carrying out home assistance. Information and training must also be relative to the problems of serious brain injury such as feeding and nutrition, respiratory assistance and assistance regarding aids and the overcoming of architectural barriers.

### 3.3.2.3 Unit for serious disability in children

The Unit for the rehabilitation of serious disability in children is expressly aimed at facing the complex and serious diagnostic, assessment and re-educational problems of the results of congenital or acquired motor and cognitive, internist pathologies in childhood. It is sized for super regional areas. The Unit is divided into sub-units which, based on the pathology, are activated within the specialised hospitals where specialised treatment is guaranteed in the following fields: intensive care and intensive therapy, neonatal pathology, orthopaedics specifically oriented towards corrective interventions in child disability, neurosurgery, paediatrics, plastic surgery, neurology, otolaryngology, ophthalmology, general surgery, general medicine, physical and rehabilitation medicine, child neuropsychiatry. It must be underlined that, where the Unit for the seriously disabled child is aimed at the rehabilitation treatment of specific pathologies, the specialist departments mentioned above are limited to the specific disciplines.

The Unit for the rehabilitation of serious disability in children is equipped with beds, the number depends on how many are foreseen by the community care programme.

The Unit for the rehabilitation of serious disability in children is staffed with a sufficient number of specifically trained and qualified personnel, including neonatal specialists, paediatricians, child neuropsychiatrists, physiatrists, nurses, physiotherapists, speech therapists, neuro and psychomotor therapists, occupational therapists, psychologists, orthopaedic technicians, assistance technician operators, professional educators, social workers.

The Unit for the rehabilitation of serious disability in children is characterised by assessment and rehabilitation activities aimed at the projecting and validation of prosthetic and orthotic equipment and experimentation of innovative materials, as well as the assessment and supply of all aids suitable to the specific rehabilitation goals and to the evolution of the disability.

The Unit for the rehabilitation of serious disability in children

coordinates its intervention in extensive or intermediate rehabilitation within the health service network with which it is linked to follow disabled patients in their own community guaranteeing completion of the rehabilitation path according to well defined protocols.

The Unit for the rehabilitation of serious disability in children must guarantee the families appropriate formalised information and training and also for the people who will be carrying out home assistance. Information and training must also be relative to the following problems: respiratory assistance, cognitive problems, behavioural and psychological problems.

### 4 Equipment in the workplace of people with disabilities: Law 68/99

One of the great laws that has been promulgated in the wake of Law 104 was the law from 12th March 1999 n. 68 "Provisions governing the right to work of the disabled".

It is this provision that presently regulates the insertion in the workplace of people with disabilities and represents a deep cultural innovation concerning integration in the workplace as it has introduced an issue inspired by the concept of "targeted insertion" surpassing the vision and bureaucratic and institutional limits of the previous provision (Law 482/68).

The law promotes and supports individual insertion in the working world of people with disabilities according to an analysis of the working capabilities of the single person and of the characteristics of the place of work, encouraging the start of positive support and foreseeing therefore the removal of environmental and relational problems that make insertion into the working world difficult.

It is a law that is applied:

- to people of working age affected by physical, psychical or sensorial disabilities and to intellectually handicapped people which leads to a confirmed reduction in working capability superior to 45 percent,
- to disabled workers with a degree of invalidity superior to 33 percent,
- to blind or deaf and dumb people.

By virtue of this law people who are unemployed and aspire to a job suitable to their working capabilities enrol on a special list where each person's working capabilities, abilities, skills and inclinations are recorded, as well as the nature and degree of disability in order to be able to match abilities with the characteristics of work places to be assigned to disabled workers, favouring the match between supply and demand.

Employers, public and private, are obliged to employ disabled workers as follows:

- a) seven percent of employees if the company employs more than 50 workers;
- b) two workers if the company employs between 36 and 50 workers;
- c) one worker if the company employs between 15 and 35 workers.

### 4.1 Checks on disability conditions

Checks on disability conditions are a necessary requirement to accede to the system for insertion in the workplace foreseen by Law 68/99. For a person who possesses a work invalidity with a

degree superior to 33 percent, a registered disabled ex-service man, a registered disabled person through war or through service, the invalidity certificate previously obtained is valid also as assessment of the disability condition for insertion in the workplace. On the contrary, a disabled civilian, the blind and deaf and dumb have to undergo a specific check on the condition of their disability.

According to the most recent and agreed on international definitions of disability, a disability condition exists when there is a restriction in a person's degree of functioning in relation to all dimensions regarding functions and physical structure, the capability to carry out activities and the degree of participation in life situations.

Assessment of disability distinguishes, therefore, between civil invalidity and work invalidity.

The extent of disability is not, furthermore, directly correlated to the degree of impairment of functions and physical structure; there can be, for example, the situation where, with reference to two people with the same functional impairment, only one presents significant reductions in capability and/or restrictions in social participation. Thus, different conditions of disability and different assessments on the possibility of insertion in the workplace and on the necessary support are determined.

Concerning businesses, the provision supports the instruments which impose incentive measures

The logic of this law requires deep changes in operative methods and in investments:

- exploitation of personal working capabilities in order to guarantee the work identity of each disabled person with regards to work;
- changing of the old and inappropriate assessment logic using the indications of the International Classification of Functioning, Disability and Health (ICF) of the World Health Organisation.
- harmonisation, through special instruments, of methods of enrollment and access to work integration paths, adopted by employment services.
- guarantee of tutoring and accompanying of disabled people in the difficult path of insertion foreseeing also, when necessary, an economic intervention.

To put into practice all the actions of the new logic of targeted insertion, a large network of relations between everyone involved (school, local health authorities, Municipalities and Provinces, work integration services, associations, cooperatives, professional training services, trade union organisations) must be elaborated. To this end employment services operating on a provincial level will set up Provincial Technical Committees.

This is a matter of specific and important technical services assigned to the realisation of individualised targeted placement projects based on the:

- assessment of workers' capabilities and potentials;
- definition of the instruments necessary for insertion in the workplace
- programming of an insertion support and tutoring plan;
- workplace controls to evaluate the progress of insertion;
- drafting of professional training and requalification programmes of disabled workers.

#### 4.2 Capability assessment

To promote workplace insertion and integration of disabled people the law foresees a series of support services and targeted placing.

Targeted placing is constituted by a group of instruments for the assessment of the working capabilities of disabled people with the goal of insertion in a suitable position through:

- analysis of work posts
- forms of support
- positive solutions to problems that can arise in the workplace.

Unemployed disabled people who aspire to a job in conformity with their working capabilities can put their names on special lists that are managed by Government offices called "Employment Centres" which are located throughout the country.

For this law to be put into practice in order to guarantee work insertion suitable to the abilities of each person, it is necessary

- 1) that the capability / ability assessment in possession is suitable with regards to the task to be carried out;
- 2) that the assessment team is specifically competent and that the necessary professionals that make it up, such as the rehabilitation doctor, the therapist, the occupational therapist, the psychologist are integrated with experts in the type and place of work where the disabled person is to be inserted.

**Success strengthens the right of a disabled person to obtain a job; failure demotivates people and companies.**

#### 4.3 Occupational conditions of disabled people 5 years on from the coming into force of Law 68.

The effects produced by this law in the fifth year since its application (ISTAT survey) are interesting. Let's report some data, significant for the planning of any corrective interventions.

The survey was carried out on disabled people who live with their families to gather the main aspects of the social integration of disabled people in their everyday context (relationship network, school, work, free time, etc.).

In total 1,632 people between 14 and 67 years old were interviewed on the telephone—this represents a population of 1,641, 000 individuals of the same age bracket.

**The sample examined was made up of disabled people from 15 to 67 years of age.**

##### • Disabled people who work

To trace a descriptive picture of the relationship of disabled people between 15 and 67 years old with the world of work and to have thus indications on the level of participation/integration in this context, three groups were identified:

- disabled people who are employed
- those who have worked in the past in a disabled condition
- those who have never worked

The remaining 26.8% were not analysed as they had worked before becoming disabled but they haven't worked in their disabled condition

Disabled people who are working	26.5%
Disabled people who have worked in the past	33.2%
Disabled people who have never worked	13.5%
Disabled people who don't work but who worked before becoming disabled	26.8%

Among the people with disabilities, 26.5% are employed.



Those who have worked in the past in a disabled condition represent 33.2%.

Thus, about 60% of disabled people work or have worked in the past.

Among the people with disabilities who work, 32% are affected by a serious disability.

• **Employed disabled people: where they work and with what contract they work.**

The disabled who work are mostly employed in private profit organisations (private companies): 56.1%. Only 36.6% are employed in public organisations.

82.3% of employed disabled people declare they have an indefinite contract compared to 87% of the population within the same age bracket.

80.4% of employed disabled people work full time, a level only slightly lower than in the total population (88%).

People from 15~67 years old with disability, employed, according to the type of organisation they work for, the type of contract and the type of work for the onset of disability period.

	Disability onset before present job	Disability onset after present job	Total
<b>Type of Organisation</b>			
Public organisation	37.1%	35.8%	36.6%
Private-profit organisation	53.8%	60.0%	56.1%
Private non profit organisation	5.2%	2.2%	4.1%
Other	3.9%	2.0%	3.2%
<b>Type of Work Contract*</b>			
Indefinite time contract	75.8%	94.5%	82.3%
Fixed term contract	20.1%	2.7%	14.1%
Other	4.1%	2.8%	3.6%
<b>Type of Work*</b>			
Part time	24.3%	9.0%	18.5%
Full time	74.2%	90.9%	80.4%
Other	1.5%	0.1%	1.1%

\* The percentage is calculated for disabled people who work as employees

• **Employed disabled people: Disability previous or subsequent to employment.**

Among employed disabled people, in 62.4% of cases, the onset of disability was previous to employment in their present job, while in the remaining 37.6% of cases disability occurred subsequently.

Disability onset before present job	62.4%
Disability onset after present job	37.6%

Among people where their disability occurred before their present job, those who obtained an indefinite work contract are less (75.8%) in comparison to people whose disability occurred subsequently (94.5%).

Even concerning the type of work (full/part time), people whose disabilities occurred before their present job are disadvantaged. Among these the quota of full time workers falls to 74.2%

compared to 90.9% in those where disability occurred only after employment in their present job.

• **Employed disabled people: to find work**

About 30% of employed people declare to have benefitted from provisions regarding compulsory hiring, among men this number rises to 35% and among women it falls to 22%. Most employed people who benefitted from provisions regarding compulsory hiring obtained a job with an indefinite time contract. Furthermore, the time between insertion on the compulsory placement lists and hiring was less than a year for 37.8 % of it.

The help of family and friends seems to work most in the search for employment. Confirming this, about 31% of employed people say they found their present job thanks to their own social network, while 20% of employed people found work through participating in an open contest, 17% through public employment agencies and 16% say they replied to a job advertisement and sent in their cv's.

Resorting to a Government employment centre is prevalent among people whose disability occurred previously to insertion in their present job (22.4% compared to 8.1% of those whose disability occurred subsequently).

More than 67% of disabled people found work without resorting to State organised Centres

<b>How people find work</b>	
Help of family and/or acquaintances	30.90%
Participation in an open contest	20.10%
Government employment centre	17.00%
Reply to advertisements and sending of cv	16.20%
Other	15.80%

In latter years, among people with disabilities who are looking for their first job, almost everybody has put their name on the placement lists of the Government employment centres—the use of state agencies in the search for work is taking root among the generations that still have to enter the work market.

Law 68/99 seems to have brought about another important change: the awareness of the right to work for disabled people. People with disabilities looking for their first job, in fact, do not report in significant numbers to having encountered, when looking for work, negative experiences linked to their specific condition of disability such as feeling discouraged in the search for work, fearing isolation at work or being discriminated against in the search for work or also receiving job offers incompatible with their condition.

**4.4 Necessary aids for insertion in the workplace**

The most frequent aids needed by disabled people in the workplace are **mechanisms able to overcome ramps and stairs**, in fact, 10% of people express such a need but 24% say they are unable to make use of them.

Another support that disabled people request is **reserved parking**, in fact, 12% need this but 26% of them can't benefit from it. Finally, 8% of workers with disability say they need **work stations suitable to their condition**, but 20% say they can't benefit from this.

Accessibility must be increased and the equipment of aids

must be improved if we want to raise the number of employed disabled people and their quality (profitability) of work.

The request for disabled parking indicates that a high percentage of disabled people who work use their own car to reach the workplace.

The overcoming of architectural barriers is the first condition to permit and favour insertion of people with motor disabilities.

#### 4.5 Conclusions

Personal realisation that comes with insertion in the workplace is a fundamental condition for full social integration. For disabled people, where the individual psychophysical conditions allow it, this integration is linked both to the individual history, motivation and family context and to the existence and to the efficiency of services aimed at incentivising insertion in the workplace which can present various difficulties. It is therefore necessary to know both the state of the art of this stage in social integration and to have an outline of the services that exist and operate in the community.

Notwithstanding Italy is confronted with avant-garde legislation, analysis of the data used still highlights lower insertion of disabled people in the workplace compared to those people with no disabilities in all age brackets. A low percentage of employed disabled people is in fact recorded, around 20%, and it is noted that among the various difficulties, sensorial difficulties (sight, hearing and speech), represent the disabilities that are more easily inserted in the workplace. On the other hand, multi-disabilities, as was foreseeable, seriously compromise access to the workplace.

The realisation of significant innovative elements introduced by Law 68/99 has not been completely carried out yet and most recent data highlights the percentage of activation of targeted insertion services of around 90%, with a certain national heterogeneity.

However, encouraging data is emerging from users of these services which have seen an overall increase, moreover, in a comparison between supply and demand, a substantial balance emerges.

One very interesting aspect is the analysis of the path linked to the search and finding of a job. From a more in-depth analysis it can be seen that for many of the employed it is their first working experience and this is confirmed also in the higher age bracket (44–65 years old). Such data leads to the thought that it is exactly the promulgation of this law that has ensured that disabled people are now aware of the possibility of their entering the workplace, despite their disability.

The placement services have served to insert about a third of the employed disabled people, similar to the numbers who used the network of friends and family.

If, though, attention is focused on those who are looking for their first job, it can be noted how more than half have put their names on the placement lists, a signal of a high level of trust in this service.

To conclude, a "slow but constant cultural and social transformation that concerns work and social policies in favour of people with disabilities", seems to be emerging. Such a positive trend should be further encouraged and monitored by competent public institutions.

#### ISTAT: Italian National Institute of Statistics

**Note:** The Italian National Institute of Statistics is a public research organisation. It has been present in Italy since 1926, and is the main producer of official statistics in the service of citizens and policy-makers. It operates in complete independence and continuous interaction with the academic and scientific communities.

Since 1989 ISTAT has been performing the role of directing, coordinating, and providing technical assistance and training within the National Statistical System (SISTAN). The System was established under Legislative Decree 322/89 in order to rationalise the production and publication of information and to optimise resources allocated to official statistics.

SISTAN is made up of ISTAT, central and branch statistical departments of Public Administrations, of local and regional bodies, Chambers of Commerce, other public bodies and administrations providing statistical information.

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