

## Historical Evolution of Disability Concept

Massimo Fioranelli<sup>1\*</sup> MD and Maria Grazia Roccia<sup>2</sup> PhD

<sup>1</sup>G.Marconi University, Rome, Italy

<sup>2</sup>University B.I.S. Group of Institutions, Punjab Technical University, Punjab, India.

Received March 28, 2015, Accepted April 16, 2015, Published April 22, 2015

### ABSTRACT

The very first moments of life are extremely delicate for all ancient Romans. By law that baby is not yet completely "born" but is so only when the father takes it in his arms and lifts it up to the sky. The baby that is not lifted by the father - and therefore not legally recognized - can be "exposed", that is to say abandoned or killed.

In the Christian Middle Ages the birth of a deformed child is an attack on nature's perfect order, a divine punishment and an unmistakable expression of God's rage.

The inheritance first and second world war was 15 million dead, 8 million invalids, mutilated and blind. This dreadful and unprecedented tragedy has the disconcerting power of dragging an enormous number of people down into the infernal circles of the handicapped (physical, mental and sensory). Despite being stigmatized, the war veterans gradually begin to be looked after. The state does this by means of the newly established public health and some embryonic forms of Social Security.

*Lebensunwerten Leben*: life unworthy of life; life that does not deserve to be lived. *Gnadentod*: death by grace or mercy killing. One of the most horrific events of the twentieth century rotates around these two expressions.

On May 3<sup>rd</sup> 2008 the United Nations Convention for the rights of disabled persons comes into effect. It strongly reaffirms those fundamental rights and freedoms that mean full social, political and economic participation by all people with disabilities (men and women) in all countries they were born and live in.

**Keywords:** Disability; Disease; History; Impairment; Disablement; Handicap.

### INTRODUCTION

This paper is a brief digression through the ages, to evaluate the importance and changes in the attitudes of various cultures and populations towards the physical and mental handicap.

The welfare system needs a new definition of the term "disability". The recent Convention on the Rights of Persons with Disabilities of the United Nations [1] mark a turning point on the big issue of human rights. The article 1 state: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." [1].

From this statement we analyze the characteristic elements of disability: body perturbation that produce a functional or anatomical damage that interacting with the contest limit and reduce the social participation of people.

Disability is a multifactorial condition and physical, social and environment contest define itself.

Aim of this work is analyze the evolution of disability concept through the ages.

### The Graeco-Roman World

« We suffocate monstrous foetuses, and even our own children - if they have turned out disabled or abnormal - we drown them. However this is not anger, it is reason that separates useless beings from the healthy » [2]. These words written by Lucio Anneo Seneca in 41 A.D. take us straight to the heart of the matter. In the pre-Christian world to separate the "useless" beings from the "healthy" ones is a perfectly "reasonable" practice. In ancient Rome the deformed newborn is killed immediately by means of suffocation or drowning. This is not a choice, it is an obligation: it was already written five

**Corresponding author:** Massimo Fioranelli, G.Marconi University, Rome, Italy, E-mail: [segreteriaamassimofioranelli@gmail.com](mailto:segreteriaamassimofioranelli@gmail.com)

**Citation:** Fioranelli M, Roccia M (2015) Historical Evolution of Disability Concept. *Hist Med Ethics J* 1(1): 1-9.

**Copyright:** ©2015 Fioranelli M, Roccia M. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

hundred years before Seneca in the Law of the XII Tables which under point IV in dealing with the relationship between parents and children states: «*Cito necatus insignis ad deformiate puer esto*»: «the obviously deformed newborn must be killed immediately».

In fact the very first moments of life are extremely delicate for all ancient Romans, be they healthy or diseased. Healthy: as soon as the baby is taken from the maternal womb, the midwife takes it before the *pater familias* and places it at his feet. By law that baby is not yet completely "born" but is so only when the father takes it in his arms and lifts it up to the sky. *Tollere liberos*, lifting the children, is the expression which indicates the coming to the world of the new human beings. It is interesting to note the etymological affinity between *tollere* and the other verb *tolerare* (tolerate).

The baby that is not lifted by the father - and therefore not legally recognized - can be "exposed", that is to say abandoned. This can be outside the front door or on a pile of refuse. In some cases they are picked up by someone, if not death awaits them. The reasons which drive a father to decide on exposition are numerous: it could be in order not to change the inheritance will, it could be a suspicion that the infant is borne from an adulterous relationship or even the impossibility of feeding another mouth. Likewise they are all forms of neonatal disability by paternal decree.

In the case of the baby being deformed its fate is doomed - it will not even be exposed - it will be killed. Sometimes the midwife's secret pity, or that of the servants can save it from immediate death (thus delivering the baby, and themselves, from the paternal authority): but the infant's chances of survival are practically non-existent. Therefore, in the Roman world neonatal physical disability is practically impossible, seeing as it is unacceptable.

However a disability can occur in the course of one's life. What effects does this have? We must point out that for the citizen of Republican ancient Rome, the integrity of the body goes hand in hand with the honour of the *cognomen* or the *gens*. The body cannot lie, it is a man's visible reality. It is thus both a duty and a necessity to take the utmost care of it as it is not merely appearance, but also substance, and a documented guarantee of the authentic quality of a person.

On the basis of these observations it is not difficult to comprehend the profound motives justifying the suppression of a deformed baby, and furthermore, to understand the difficulties that a man who became deformed during the course of his life faced.

There is the case of the legionary who returns seriously wounded from a military campaign. He has fought for Rome, and so Rome welcomes, thanks and honours him but has no use for his tortured and injured body. This war veteran who is *deminutus* is no longer a perfect citizen. For

example, he is in no condition to be sacrificed to the gods as the body of the sacrificed must be perfect, as does the body of the sacrificial animal. The war veteran returns home, but apart from the right to vote, he is forced to the sidelines of civil life. In his flesh he painfully bears the stigma of Rome's grandeur, but unfortunately his disability makes him both a hero and a half-man at the same time.

It is here that the concept of stigma is introduced: a physical branding, a permanent blemish which marks a person forever, for the better or the worse. In ancient times it also marked the bodies of delinquents and slaves. For people suffering from disabilities, in every place and period of history, the physical stigma also became a moral one. According to the Canadian sociologist Erving Goffman, there are three fundamental types of stigma. The first is caused by deformities and disabilities (Goffman places character flaws second. The third type is tribal stigmas of race and religion).

According to Goffman deformities and physical disabilities cause a strong discordance between the idea of a person and the person them self (when faced with someone's physical appearance it is possible to classify them, but when faced with a body or behaviour that is different from one's own, it is difficult to do so). Therefore the disabled person - in the same way as the diverse, the stranger or the foreigner - «is relegated from being a complete person, to whom we are commonly accustomed, to being a marked person.» This is because they lack that *something* necessary to include them in a recognized category. This shortcoming is a negative stigma, especially if it causes «deep discredit» [3].

The Roman war veteran with all his wounds and mutilations carries a negative stigma. Although he is a national war hero, in the citizen's eyes he is marked for life in spirit and body. His life will never be the same again.

Let us take step backwards to ancient Greece in order to understand how individual physical decay, the handicap, could sometimes evolve into an extremely positive and advantageous opportunity for the whole *polis*. The "branding" of a person - in order that the whole community can recognize its essence and function - is a widespread practice for the ancient Greeks, one closely connected to the idea and figure of the scapegoat.

In a city devastated by famine, plague or a lost war, the town worthies choose a subject (man, woman or both together) who symbolically weighed down with all the sins of the people, is put to death in order to restore health and prosperity to the nation (the rite was also practiced in Rome when under threat by Hannibal). But who is this subject? How is the scapegoat chosen?

The greatly respected Scottish anthropologist James G. Frazer (1854-1941) stated: «The Athenians regularly kept - at the States expense - a certain number of degraded and useless creatures, and in times of plague,

drought or famine two of these hapless souls were sacrificed». He continues: «The custom of the scapegoat practiced by the Greeks in Asia Minor in the VI century B.C. was the following: when a town suffered a plague, hunger or other public calamities, a deformed or ugly person was chosen to bear all the ills affecting the community. The chosen person was taken to a suitable location [...] where he was beaten seven times on the genital organs with squills, wild fig branches and the branches of other wild trees, while others played a special melody on flutes. He or she was then burned on a stake made of forest tree wood and the ashes thrown to sea» [4].

As long as degraded, useless, ugly, deformed and disabled people were used as scapegoats; at least they had a positive role to play in the communities they belonged to. In this sense it is interesting to note how the Greek word to define a scapegoat victim is *pharmakós*, and how this has the very same etymology as *pharmakón*, that is to say cure, remedy, a substance of therapeutic value (but also: poison). To sum up: From being degraded, useless, ugly and deformed, the figure chosen for the role of the scapegoat transfigures and becomes a miraculous and potent medication that saves his country and people. It is through this ritual death that he or she is redeemed from a miserable and foul life.

Regarding neonatal disability in the Greek world, the same situation as described for the Roman world applies. Here too the deformed baby is suffocated or exposed as well. Furthermore, exposure can be even be carried out in advanced infancy if a disability occurs or becomes evident.

However there is a considerable difference with the Roman world concerning disabilities incurred during the course of one's life (and in particular regarding war injuries). The citizens identification with their own bodies is felt less strictly than in Rome. The soldier who returns home mutilated can be treated, and therefore even receive a primitive form of social welfare in the form of a mite handed out occasionally to compensate for the inability to work. This must not in any case be mistaken for the invalid's complete reintegration into society, as this did not occur in Greece or Rome.

But who or what caused the birth of a deformed baby? Well, the creature with coiled feet or with too many fingers on his hand is the clear expression of divine anger; a fatal omen, a bad spell. It is possibly the incarnation of a known or unknown misdeed already carried out, or yet to be committed.

The wrathful God shows its power and disrupts the fluids for the insemination; the sperm in man and the menses in the woman. An improper combination, an excess or a sudden shortage generates the *tèras*, the monster. The latter can also be generated by bestial couplings: as in the story of

the Minotaur, who is said to have been born from the ghastly copulation between a woman and a bull.

This is the belief of many philosophers and doctors. It also the conviction of Aristotle, whose influence, as we know, lasted through the centuries. A physical deformity - even when observed in the tiny body of a newborn - is a stigma, a badge of shame which reveals a misdeed to the whole world.

Those affected by disability, but who have a sound body, have a very different fate. This is the case of the blind, deaf and insane. They are tolerated, and in some cases, even with a thousand difficulties, held in special repute.

The blind, for example, despite not being able to see the present, are thought to be capable of seeing the future. This is thought to be due to their highly developed other senses, a sign of a special kindness from the gods. It is not a coincidence that many renowned soothsayers in history have been described as blind.

The persons who show a mental deficiency often provoke fear and even respect, due to the fact that they are not understood. Again, one imagines the deficiency as a vehicle for some sort of supernatural sign. It is thought that even if gestures and words are confused and nonsensical, they are expressions of a divine will. This is all in principle. In real life it is more likely that the mentally ill are segregated indoors and hidden from view. It is very rare that their prophetic virtues are taken into consideration.

«You are blind in the ears and mind, as you are blind in the eyes» [5]. This is what Oedipus shouts at the soothsayer Tiresias, who has just revealed the terrible truth that makes him a parricide, and also guilty of incest with his mother.

The tragedy of Sophocles places us before two different disabilities at the same time. Tiresias is blind, while Oedipus is lame (his name means "he who has swollen feet") These two disabilities have very different meanings and importance.

Tiresias is not born either blind or a soothsayer, but becomes so due to a punishment inflicted by a goddess. Some claim that it was Era who blinded him for having revealed a truth which would have best been kept secret to Zeus. Others claim that Athena was responsible for blinding Tiresias as Tiresias had seen her bathing naked and was therefore never to see again. Whatever the story, the poor man is given a gift - As compensation he will now be able to see anyone's past and will know the future.

This how Tiresias is able to tear Oedipus's veil of ignorance. The latter unknowingly shed his father Laius's blood, and was guilty of the terrible crime of maternal incest. And to think that Oedipus is lame because his father exposed him as a newborn exactly in order to avoid this tragedy (supposedly written in his destiny) by ordering that

the baby be hung upside down by his feet, and thus causing the deformity.

His handicap (stigma) would thus have been "natural", and not caused by the father's decision. The boy grows up and then seeks revenge for his parents refusal. In this case, the story would assume a very different significance: but it would no longer be Sophocles[6].

### **The Middle Ages and The Renaissance**

In the Christian Middle Ages the concept of disability for misdeeds did not recede. Far from it - the idea strengthened and spread. The birth of a deformed child is an attack on nature's perfect order, a divine punishment and an unmistakable expression of God's rage. However, now the dock is no longer empty, but is definitely occupied by the mother, guilty of having given birth to a child who is the son of sin, adultery and the devil. She is the one and only protagonist of a monstrous and unnatural sexuality and the unfortunate child is the tangible proof.

The stigma brands both the little deformed child and the woman who gave birth to it. In the course of the last thousand years many women have been charged with having slept with Satan, and even accused of witchcraft. Their fate was to be burnt at the stake, sometimes alongside their child. The idea of a horrific promiscuity, or even an alliance between the woman and the devil has continued in the recesses of popular belief until quite recent periods and is die hard.

In an era where medicine is still unable to explain or give plausible answers, then the only voice able to guide Man along these frightening and inaccessible paths, is the word of the Church. If Pope Gregory the Great, the successor to Peter from 590 to 604, is convinced that a healthy soul cannot live in a diseased body, then he is to be believed. It is again strongly stated that the disabled person is also morally ill; that the infirmity should be interpreted as an external sign of the rot corroding the soul.

Although officially the practices of suppression and exposure of wretched children have been abandoned, their destiny is in any case in the hands of those who welcome them into the world. Therefore in the very first moments of life, the Roman figure of the pater is substituted by the midwife. It is she who first learns the truth; and after having been purposely instructed by the ecclesiastical authorities, it is again she who decides on the fate of those newborn who having been judged as non-human, would not have the right to be baptized anyway. So the midwife can have the faculty of killing the monsters, and it is not to be excluded that she sometimes decides of her own initiative to spare the newborn and the mother from a future of abuse and suffering. It would then be sufficient to simply claim that the child was stillborn.

Having overcome the tough challenge of birth, everything now depends on the family's economic condition. The rich have the possibility of choosing; of either keeping the deformed child and bringing it up secretly hidden away in the house, or of giving it away and abandoning it to its own destiny. The poor, who survive exclusively by means of manual labour, have only the latter choice.

Medieval cities were swarming with beggars, many of whom were invalids. They have been denied the chance of living a dignified life, but they do have the "right" to survive by begging, provided that they follow the rule of keeping the devastated parts of their bodies well in sight for everyone to see. However strange it may seem to us, the medieval beggars were not really outcasts. In fact, they are a necessity in order for us to perform acts of charity. They are also organized, established and live following the rules of human society [7].

It is here that one of the great changes of the Middle Ages comes about: the notion of charity. Although the disabled person has his guilt written all over his body, it is also true that he or she bears public witness of human weakness. Therefore, it is the duty of every good Christian to observe that illness through charitable and compassionate eyes. After all, the gospel of Matthew states that in the act of curing the diseased, Jesus « Brings our ailments onto himself and carries our diseases» [8]. Saint Augustine also warns us that faith is expressed through charity.

Therefore, the presence of invalid beggars in the streets, squares and at the gates of medieval cities is important. These individuals are socially and morally stigmatized, but not completely banished from a world that needs them, in order to feel in harmony with God. Whether these beggars are settled or travelling (those who can move from town to town earn more), they still occupy a place in society, even if it is at the bottom rung of the ladder. In the end, the way they are forced to live ends up resembling a job. This consists in exciting pity by displaying their wounds and deformities. The most skilful get the highest reward. It is not uncommon for perfectly healthy individuals to disguise themselves as seriously ill, putting on non-existent diseases to scrape a few coins together.

The fierce social crises, which periodically disrupt the medieval world, caused by famine and war, drastically change the attitude towards beggars. A "war between the poor" during the course of which many behave in a harmful and marginalizing way towards the weaker subjects in society.

Some diseases such as leprosy, excite no pity, although they are crippling. The leper must immediately be isolated from the rest of the community. Due to the danger of infection, purpose-built hospitals for the chronics are set up and these must necessarily be situated extra moenia or

outside the city walls. The act of separating the diseased from the world of the healthy is celebrated like a solemn funeral; crowds accompany the diseased to the gates of the city to which he or she will never return. With no possibility of being cured - he is in fact the victim of a terrible decay and of a «gangrene that passes from the soul to the body»<sup>7</sup> - the leper is excluded from the community forever. The leper will go to live in a leprosarium on the fringes of what was once his or her world. Any contact with the healthy is prohibited, and if the leper is still able to walk, he or she must carry a rattle around the neck to warn passer-by's of his or her presence.

However, it is the town itself that ensures the survival of both the lepers and the leprosarium by means of substantial donations in money and food.

A medal also has its reverse side. The iconography of the Renaissance and the Medieval court often shows us strange figures whose very presence is somehow “out of place” with their surroundings, and with what we have said so far. What are these hunchbacks and dwarves doing next to the king and his devotees? Are they not monstrous beings too? Affected by deformity, the dwarf and the hunchback certainly contradict the natural order, to which they are outsiders. But it is precisely due to this obvious diversity that they are recognized as possessing extraordinary gifts and faculties.

It is as if they are encircled by a magic halo which protects them from the rage and revenge of Man. They are alone in being allowed to blurt out the truth in the prince's face, to mock him and to deride power. In other words, to point out that the “emperor has no clothes!”

No sane or healthy man could venture so much without putting his own life at risk. But dwarves and hunchbacks, who are enthusiastically welcomed at court (and often even listened to), can take the liberty of all this, with powers who are otherwise lacking in magnanimity and generosity.

Therefore, this time the stigma is of a positive nature.

The Church starts to include all those who for various reasons find themselves in conditions of difficulty, in the extensive category of the “afflicted”. These are the physically and mentally disabled, the poor (poverty is often synonymous of infirmity) those on the fringes of society and the diseased in general. People who are – we repeat – stigmatized by society, but who are given charitable help that is the expression of Divine mercy.

It was during the Middle Ages that the first hospitals and special institutes were set up to take care of the needy and to relieve this suffering. These structures were run by religious orders and offered free shelter and aid to many of those forced to live a miserable and wandering life.

The idea that led to the birth of these structures is a direct result of the notion of charity. However, there is certainly also the clear intention of “separating” the sick from the healthy – here again we see Seneca's words which we started this brief journey through time.

Separating the sick from the healthy means hiding them from sight that can wound the eyes; it means protecting the healthy from the excesses and violence of the insane. It also means organizing a powerful instrument of control over all forms of “deviance”, whether due to disease or an expression of antisocial behaviour.

A further separation, this time between the patients starts to gain ground towards the middle of the sixteenth century with the foundation of the first “madhouses” (like Santa Maria della Pietà, in Rome). These are a sort of ante litteram mental asylums where the demented are kept and attempts are made to cure them. However, the notion of dementia is still very vague and ambiguous (it will remain so for a long time) so it follows that these structures also take care of men and women who showed signs of unruliness and rebellion against the authorities, society or their families.

In the Tridentine catechesis, which was approved by the Council of Trento (1545-1563) and promulgated by Pius V in 1566, point 287 makes precise reference to who is worthy and who is unworthy of wearing the priest's habit and administering the sacraments. The list of the unworthy – after young children, the insane, slaves, the bloodthirsty, murderers and bastards – also includes those «deformed by serious bodily defects and the crippled. Deformity is repulsive and this disability can bar the administration of the sacraments. » The Tridentine remained effective until the New Catechesis instituted under John Paul II in 1992.

### **The Eighteenth and Nineteenth Century**

Medical Science underwent an extraordinary period of development starting from the end of the eighteenth century and then more substantially in the course of the nineteenth century. The role of the doctor became better defined, especially with regards his role in society. In fact, the doctor becomes a sort of intermediary between the citizen and the powers of authority: he caters for the needs of the former and represents the smiling face of the latter's will and need to create order.

In this sense, medical progress opens new scenarios. It now becomes possible to classify illnesses and therefore to increase the control and repression of deviances. In this way, hospitals become centres for both treatment and “record keeping”. The separation between the diseased themselves (the curable on one side and the incurable on the other), early signs of which were visible in previous centuries, definitely gains ground with the establishment of the new idea of “rehabilitation”.

Depending on the seriousness of their problem, the invalid can be rehabilitated. We must underline that this does not mean fully re-introduced into society, which still prefers to keep them hidden away and marginalized, but still useful.

On the other hand, mental disability, which is scarcely understood and let alone treated, means being condemned to definite internment. It is not until 1793 that French doctor Philippe Pinel sensationally frees the demented from their chains in the Parisian hospital of Bicêtre. In 1800, he then publishes his *Medical-Philosophical Treatise of mental alienation*, which many «consider to be the “theoretic event” which officially marks the birth of Psychiatry. The treatise states the possibility of curing madness by means of two main strategies; the isolation of the patient from the outside world, and “moral treatment” aimed at distracting the insane from their obsessions to bring them back to reason» [9]. Therefore, to lock up in order to cure, or rather, to lock up “and” cure. This is an important step forward in form, even if, as we will see, in substance things will remain unchanged for almost two centuries.

While the birth of the modern state makes it necessary to control deviance through the expertise of doctors, it also introduces an important change in the form of the institution of the public hospital. In the Middle Ages, as we have noted, hospitals were the most tangible result of Christian charity, and therefore had an exclusively religious matrix. Before the seventeenth century is over we witness the development of the first structures instituted and run by the state, these hospitalized the ill and took care of the terrible effects of disease and poverty. In 1674, the *Hôtel des Invalides* was founded in Paris. It was built to give mutilated soldiers shelter and to guarantee their economic survival.

In these hospitals the intention of control and repression where necessary, is much clearer, and is especially evident in the attempt to divide the mass of invalids into distinct categories. We have already mentioned the early mental asylums, while the creation of institutes, which exclusively hosted soldiers, expresses two concepts; the States gratitude to those who fought heroically, and the urgency of immediately eradicating any possibility of rebellion or discontent due to poverty among those who no longer had arms or legs enabling them to work for a living.

At the end of the seventeenth century, near Milan, in Italy, the “Pious Home for the disgusting, impotent and incurable poor” is founded. This is one of the first institutes not run by the Church, and is located in a former hospital confiscated from a religious order.

The Industrial Revolution – which we can date to beginning in 1760 – changed the forms of employment, but also the face of disability. There is the first appearance of the invalids and mutilated who have sacrificed their eyes and

limbs to that undisputed totem that is the steam engine. These are men in the prime of their physical strength, born healthy and untouched by disease, and who suddenly find themselves physically broken and no longer able to earn a living.

It is a difficult situation, as industrial development has produced entire new working class areas situated in the periphery of the big cities, populated by people who have emigrated from the countryside in search of subsistence. It is in these areas, which are increasingly looking like ghettos, that for the first time one can witness the devastating and alienating effects of progress: poverty, filth, alcoholism, domestic and social violence and all types of disease. In addition to these, there is also the progressive and unstoppable increase in permanent disabilities. These render the victims unable to work and literally turn entire families into down and outs. It is a ticking time bomb, which the state cannot ignore.

Therefore, the first forms of public social welfare are established. These are basic and limited, but do have the aim of assisting the workers, especially if they are injured, and where possible of avoiding the risk of revolt or uprisings. Once again, the doctor who lives and works in these neighbourhoods has the double role of clinician and “controller”, and who must be ready to denounce any sign of revolt and to report the reasons for this discontent so they can be acted upon.

The delay with which industrialization occurs in Italy means that the problem is postponed to later years. In fact, the first state interventions in Italy are carried out in the post-unification years. These only take shape concretely in 1898 with the creation of the National Security funds for invalidity and old age. However, the aid is not yet obligatory, and only becomes so in 1919.

In the nineteenth century the combination of the desire to rehabilitate (including the body) and the growing number of mutilated, has the effect of the great development in orthopaedic instruments. These are rudimentary tools, such as busts, collars and wooden legs, but they are also the first timid evidence that something is starting to change in the common perception of handicaps. At least now, apart from separating them from humanity, someone is “looking” at the disabled, observing and studying them. Solutions are being found and in the years to come these will be improved and applied more diffusely. This is a giant step forward from the pure and simple mark of infamy.

Louis Braille became blind as a child. He lost his left eye at the age of four while messing around with his father's tools in his saddle workshop. Shortly afterwards an infection also took his right eye. In 1816 Louis is six and proves to be bright and intelligent, so his family decide to send him to the Youth Institute for the blind in Paris. The institute was founded in 1784 by Valentin Haüy, an

enlightened pioneer in the field of the education of blind children. The institute focuses on trying to teach the young children a trade – such as weaving cane seats for chairs – but this is not all, as Haüy himself has come up with a method that enables the blind to read. It is a simple and rudimentary method, but it works. It involves the use of another of the senses: touch. The children learn to recognize the printed characters highlighted by copper wire on the back of the page. Louis can now read, but it is still not enough; he wants to be able to write as well.

The idea comes to him during one of the occasional visits that well-known characters of that era used to pay to the institute. An officer tells the children about a system that the army is perfecting that allows soldiers to read important dispatches in the dark. The system is based on the combination of twelve projecting points.

Louis is dazzled and immediately gets down to work. He makes every effort to simplify it, and reduces the number of points from twelve to six. In circa 1830, he patents his own reading and writing method for the blind: the Braille method.

### **The First and Second World War**

15 million dead, 8 million invalids, mutilated and blind. The insane, the “war fools are innumerable.

The inheritance from the Great War (1914-1918) is summed up by these figures. This dreadful and unprecedented tragedy has the disconcerting power of dragging an enormous number of people down into the infernal circles of the handicapped (physical, mental and sensory). Every family is affected, and if it is not ones own then it is a neighbour. There is not a single community spared from the drama. In a certain sense, with the First World War, disability becomes a “mass” problem [10]. The problem is immediately so serious and urgent that even in Italy, with the war still raging, the National Institute for the mutilated and war invalids is founded (1917).

The disasters of war inevitably bring about a series of important changes in the way that disabilities are seen and treated. All these people who against their own will now find themselves condemned to a life of suffering and exclusion all have one thing in common: They are all victims of the “State”, in the sense that they have permanently lost their physical or mental integrity serving their duty as soldiers. This is nothing new, but what is new is their frightening number.

It is no longer enough to confront the problem by organizing “separation”, confinement and internment. It is also unconceivable to apply the notion of guilt (social and religious) which was used in the past to explain diversity to this category of people. In this sense, the war invalid cannot be blamed. His only fault was that of obeying orders and being in the wrong place at the wrong time.

Despite being stigmatized, the war veterans gradually begin to be looked after. The state does this by means of the newly established public health and some embryonic forms of Social Security. Medical science contributes, taking advantage of technical progress, by developing and improving on the concept and practice of substituting missing limbs. With the distribution of the new prosthesis’s the idea of the reintegration of the disabled into society continues to grow. This is an important improvement on the mere rehabilitation linked to possible exploitation of the disabled as part of the workforce.

All this also has the effect of improving the lives of those suffering from disease and congenital deformities. However, they still have to climb the highest mountain, as the persistent and common feeling of horror due to the diverse nature of their handicap shows no sign of abating.

The Second World War (1939-1945) replays the same identical drama, only that this time the numbers are shockingly higher. The total number of dead rises to 55 million, with 24 million injured soldiers. However, the horrific novelty is the number of injured civilians. The total number is imprecise and approximate, but the figure is given as 32 million. A huge mass of people of both sexes and of all ages, is mangled, blinded and driven to insanity by the bombs and mines. In 1945 the drama of disability cruelly touches all levels of society.

### **Hitler and “Life Unworthy Of Life”**

During the Nüremburg trial, a witness refers to have heard doctors Hevelmann, Bahnen, and Brack announce during a private meeting in Berlin in February 1940, that the government of the Reich had enacted a special measure. This authorized “the elimination of life unworthy of being lived” with particular reference to the incurable mentally ill [11].

The doctors were most likely referring to an internal order signed by Hitler himself. In September 1939 this order stated that two functionaries – one political and the other medical – had been assigned to select a certain number of doctors and authorize them to grant “death by mercy killing” to the incurably ill following human judgement.

Lebensunwerten Leben: life unworthy of life; life that does not deserve to be lived. Gnaden Tod: death by grace or mercy killing. One of the most horrific events of the twentieth century rotates around these two expressions. In other words, the extermination of the mentally ill and the disabled in general that was carried out with bureaucratic ferocity by the Nazis.

Upon receiving the order from the Führer, the machine is set in motion with name of Aktion T4 (from the Tiergartenstrasse, the Berlin Street where the program’s

operative headquarters was based). The directors of the mental asylums and institutes that host the ill are all sent a questionnaire. They are asked to indicate and specify the condition of the patient's health and their possibilities of recovery. It is claimed that this is in order to evaluate their chances of joining the nations workforce, but the real truth is kept secret not arouse suspicion or cause alarm.

Many of the patients have been "trained" to work and are to all effects a good source of income for the institutions that host them. The directors are unaware of the real reasons for these enquiries, they therefore exaggerate the gravity of the conditions of health of their patients in order not to lose both money and workers. The majority of them are declared unfit to work.

Thus, the directors condemn them to death. This is put into practice by means of a list of all the ill patients (between the ages of 6 and 93) to be taken away on an established date. The directors are not informed of their destinations to avoid them from informing the families of the victims.

However, we know where those buses with their blacked-out windows and a heavy human load are headed: they are going to Grafeneck, Hadamar, Hartheim, Bernburg, Sonnenstein and Brandenburg – the six centres set up especially for the extermination. The 60 thousand oblivious and helpless people that get off those buses die almost immediately – most of them within 24 hours – killed by a lethal injection of Luminal, Veronal and Morphium. Their bodies are cremated.

Following the protests of the families and the Protestant and Catholic Church, the Aktion T4 is officially suspended. However, the extermination continues unofficially in other death camps. In May 1945, the final figures amount to 200 thousand dead.

### **From The Post-War Period to May 3, 2008**

«Every citizen unfit to work and lacking the necessary means to live has the right to maintenance and social welfare. The workers have the right to be provided for and guaranteed due means for their needs in the case of injury, illness, invalidity, old age and involuntary unemployment. The disabled have the right to education and professional training. The duties stated in this clause must be undertaken by State organizations and institutes».

This is stated in article 38 of the Constitution of the Italian Republic, which takes effect on the first day of January 1948.

In this sense, our Constitution is in line with the current United Nations Declaration of Human Rights, which states: «All human beings are born free and with equal rights and dignity. » It subsequently underlines that every individual has the right to security in the case of illness or invalidity.

Everything changes with the end of the last, terrible World War. As we have seen, just a few decades earlier such a clear statement of principle would have seemed impossible, and not only in our country. It is as if this horrendous tragedy had suddenly opened up hearts and eyes. Now there is finally the birth and real development of forms of social security, public health care and the rehabilitation of disabled people into the labour market.

Therefore, we are in the presence of a statement of principle, which will bring about laws that will drastically change the status of the disabled. From the abyss that history had condemned them to, the disabled have slowly risen up to becoming to all effects people with rights and new possibilities.

Such fine and important words must now find a practical application. The welfare state that intends to (and must) take care of these people, and guarantee them assistance and opportunities, needs to know the effective condition and genuine needs of these people. Therefore the State turns to the doctor, who once again – and as has often happened in the course of time – finds himself carrying out the key-role of the intermediary between the citizen and the authorities. In fact it is the doctor who decides the "percentage of disability", by consulting special medical tables he or she has helped draw up. In practice, by quantifying pain and discomfort, the doctor sets in motion the chain of "rights" to be acquired in the health and social fields. It is an extremely delicate and sometimes difficult role, where not only good intentions, but also shared certainties are necessary.

In order to advance along the path to full integration it is indispensable to give a clear answer to some questions. What is disability? What effects does it have? Who is the disabled person? Are all disabilities the same? It is both urgent and fundamental to resolve these queries.

A first attempt is made in 1980 by the World Health Organization, with the approval of the International Classification of Disabilities and Handicaps (ICDH). This classification is based on three consequential concepts: impairment, which is the pathology (disablement, if it is congenital); disability, which is the effect (or effects) of the pathology; handicap, which is the social disadvantage experienced as a consequence of the impairment and disability.

The ICDH with its imperative sequence of ("if A, then B, then C") soon shows its limits. Firstly, there can be an impairment that produces a handicap and no particular disability. Let us try to give an example: the impairment classified as "disfigurement" can originate an "occupational" handicap, without passing via other forms of disability ("if A, then C")

Furthermore, only pathological factors are taken into account and there is no mention of the environmental

factors (where one is born, where one lives). These factors are just as important, and in some cases even decisive.

The third problem concerns the possibility that the handicap may be caused by a temporary impairment, rather than a permanent one.

These objections have been accepted by the WHO and in 2001 it approved a new classification, the ICF (International Classification of Functioning). This substitutes the terms impairment, disability and handicap with the broader terms of corporal functions and structure, environmental factors, activity and participation. Starting from the choice of wording, it is possible to appreciate the effort being made to tackle the problem from all angles and of opening up to increasing perspectives.

This is a necessary effort to manage what finally appears for what it always was, a manifold reality.

On May 3rd 2008 the United Nations Convention for the rights of disabled persons comes into effect. It strongly reaffirms those fundamental rights and freedoms that mean full social, political and economic participation by all people with disabilities (men and women) in all countries they were born and live in [12].

These are not new words. Nonetheless, it is necessary to repeat them so that they do not remain mere words, but are transformed into facts on a daily basis. In some parts of the world this is still a long way from becoming reality.

Finally, the Convention acknowledged a concept we would like to underline: "Disability is the result of interaction between people with impairments and behavioural and environmental barriers. These barriers prevent their full and effective participation in society on the basis of equality with others."

This amounts to saying that the concepts of "normality" and "disability" are linked in an indissoluble way to the perception which – depending on the time and the place – a society has of these two conditions. In short, it is a matter of "points of view". Moreover, at the end of this quick journey through time there is no doubt about which ours should be.

Today there are 650 million disabled people in the world [10].

## REFERENCES

1. United Nations (2006) Convention on the Rights of Persons with Disabilities.
2. Seneca LA (1994) De Ira, 15.2, trad. Aldo Marastoni, Rusconi.
3. Goffman E (2003) Stigma. L'identità negata, Ombre Corte.

4. Frazer JG (1965) Il ramo d'oro, Boringhieri.
5. Sofocle (1980) Edipo re, trad. Manara Valgimigli, Sansoni.
6. Simone Korff Sausse, Da Edipo a Frankenstein. Figure dell'handicap. Ananake, Torino (2009).
7. Geremek B (1987) L'emarginato, in L'uomo medievale, a cura di J. Le Goff, Laterza.
8. Sacra Bibbia, Matteo, 8.16,17; come citazione di Isaia, 53, 4.
9. Roscioni L (2003) Il governo della follia, Bruno Mondadori.
10. Scianchi M (2009) La terza nazione del mondo, Feltrinelli.
11. Agamben G (1995) Homo sacer, Einaudi.
12. ICF (2008) Classificazione Internazionale del Funzionamento delle Disabilità e della Salute. OMS Ed, Erickson.