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Medicine and disability: historical perspective

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Abstract. Disability expresses an object, but principally also a concept with an outline difficult to define. A concept as much undefined as complex. In comparison to its definition, disability as a concept has not yet been untangled definitely even due to the fact that disability represents by itself the difficulty to trace a stable and certain dividing line. With an historical perspective, the present paper offers a discussion of the so-called interpretative models linked to the meaning and the magnitude of disability under a first medical and then sociological point of view. During last decades, in fact, the understanding towards sociological instances in relation with disability have changed remarkably, trying to bridge the gap existing in the past, when disability was observed only as a personal health issue and consequently only under one specific framework of analysis, abstracting it from the boundary conditions and from the society in a de-constructional approach which lead to disregard disability per se. Thus in the times, disability passed from being a personal and medical problem to a phenomenon with its own social impact and a social construction, deviating the observation of disability from the medical and health point of view to a holistic approach, even if with consistent differences in relation to the diverse paradigms of interpretation.

Key words: disability, diversity, models, paradigms

Introduction

Along with UN estimation data, disability affects one out of eight people in the world (1).

Disability expresses an object, but principally also a concept with an outline difficult to define. A concept as much undefined as complex. In comparison to its definition, disability as a concept has not yet been untangled definitely even due to the fact that it represents by itself the difficulty to trace a stable and certain dividing line.

Descending on different ways of understanding and analysis of the disability, different models (2) of interpretation has been elaborated, in particular during last and current centuries.

The following pages offer a scrutiny of the existing models, summarised of necessity.

The analysis will start from the model based on the consideration of disability only under a medical/health point of view, where the individual perspective was exclusive, to approach to more recent and affirmed models related to the social evaluation and social inscription of the disability, where the perspective of and within the society prevailed, to arrive to the most recent models stemming from the social model and affirming a more modern concept of socio-political perspective of disability, where persons with disability are seen as full-right-citizens, with rights not only to be recognised but also fulfilled by the state and the society. Let us then analyse in rapid succession the interpretative models of disability, examining the theoretical paradigms that approach disability in various ways up to nowadays.

We shall utilise the typological approach to theoretical analysis in order to outline the basic characteristics of the various models and approach to disability during last centuries.

Medical-individualistic model

Historically, the medical approach prevailed in the history of every kind of relationship with disability and disability issues in our western societies. This approach represented the interpretation of disability using an exclusive medical point of view and was prevailing since mid-nineteenth century. Up to the upheaval arising from the late sociology attention, the medical model was therefore the most affirmed paradigm of interpretation, which read disability as a condition to be cured, healed or, at least, treated.

The observation point focused on the impairment and concentrated in finding the best way to intervene, to cure. Disability was absolutely a health issue, seen as an impediment, a personal problem of the patient to be solved thanks to medicine. The final objective of the intervention was the rehabilitation or the healing and consequently the emphasis was put onto the pathology or the impediment, in order to reach the goal of the cancelation of the impediment same or to eradicate the disability and give back a healthy body to the society.

The medical model was the right answer to the demand arising from the society linked to rehabilitation and reinsertion of those who were put aside from the productive system due to their impediments. The only way to be part again of the society and to participate in the economic and capitalist or communist system was that one related to healing and rehabilitation. Persons with disabilities were observed as patients and the focus was not on the person, but, on the contrary, on the impairment.

If one would like to understand the current relationship between disability and medicine, therefore a historical point of view is utmost necessary (3).

It is worth to say that up to nowadays there is no precise outline and no systemic formulation of this model of interpretation of the disability under a sole medical point of view (4), but at the same time it is sure that this has been the theoretic basis and the launch pad for the opponents and proponents of different interpretations. And, even if there is no written or fixed definition of the model, it has been and is still adopted by health professionals, philosophers, legal experts and carers chopped in every domain.

At the end of last century, Rhoda Olkin (5) tried to offer a plausible definition of the model:

> Disability is seen as a medical problem that resides in the individual. It is a defect in or failure of a bodily system and as such is inherently abnormal and pathological. The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible, and rehabilitation (i.e., the adjustment of the person with the disability to the condition and to the environment). Persons with disabilities are expected to avail themselves of the variety of services offered to them and to spend time in the role of patient or learner being helped by trained professionals (6).

This way of interpreting disability meant that a person who was unable to heal and "overcome it" thanks to rehabilitation and play their full part in a society created and constructed by those who had no disability was considered as a person deserving of pity, charity and compassion (7). They were viewed as living in a personal situation of tragedy, not able to fully participate in the society, as they did not fit the standard.

This is why the medical model was also defined as the "individualistic model", because of the fact that disability was interpreted and understood as a mere personal imbalance and not a social and shared circumstance.

Despite its name, this model did not relate solely to the medical aspect but its conceptual base nonetheless lies primarily in the dogma starting from the mid twentieth century within modern medicine, according to which illnesses and diseases are factors of imbalance of the underlying physical mechanisms (8).

There was no suggestion that society could change something in itself in the presence of a person with a disability. The boundaries were clear. It was the person "suffering" from the disability who was supposed to adapt to their surroundings and not the opposite. It was therefore a private misfortune, limited to the individual sphere (9) of the person who was unable to adapt to society and correct that imbalance. Disability represented consequently a deviation from the social standard that did not conform with the paradigm of what was considered normal, balanced and complete. It was an individual state of disadvantage (8) that remained personal and did not interfere even minimally with a society that made no effort to change in order to interact with people with disability.

In fact, in the social science, a specific attention has been devoted to the social aspect of the disability only lately (10), after decades of total disregard by side of the fathers of sociology (i.e. Anthony Giddens as per Barton and other sociologists). Therefore, up to some years ago, the reflections were centred on the person with disability as a person to integrate, to heal, to recover, to treat as a patient with a disease to be cured and reinserted in the social context after rehab, it does not matter gender, expectancies, attitudes, desires.

The idea of disability as an illness or something to be eliminated has not disappeared over the years and did not apply only in western society. If a medical and individualistic view is still present pretty much everywhere, I would like to emphasise how the sanctimonious and paternalistic approach - which prevailed up to the eighteenth century at least - has contributed greatly to this interpretation, when disability was viewed as a heartbreak, interpretable from a religious viewpoint as a kind of divine retribution or spiritual test and confining disability in the individual sphere, descending from an own negative dimension. In other circumstances, persons with disabilities deserved marginalisation and reclusion (11) even because differing from the paradigm of normality (12) or because of the visibility of their disability (13).

The impairment was the stigma exemplifying the reason of the marginalisation, which was necessary to avoid contamination and corruption of the integrity of the society. This was done as in the Middle Age when treating lepers and putting them into hospitals outside the borders of the villages. This was the idea linked to sterilisation of persons with disability perpetrated during the Nazi period in Europe, but maintained in the US up to the 1920s and up to 1970s century in other European countries. Eugenics represented a consequence of the obsession linked to perfection of the body as a paradigm for the participation into society.

Social Darwinism added important burdens to this conception of disability as a shame or as an impediment to the personal realisation as a member of the society. Under many points of view disability was seen as an affection of the person, who was totally absorbed by the impediment. The only way to avoid the impediment was the rehabilitation and the cure.

As a matter of fact, it descends the wide importance attributed to the medical approach to disability, seen as the only way to "solve" the problem represented by the impairment.

This approach to the person with disability was utilised as the only one interpretation of disability and still nowadays is seen as the origin of a history of discrimination towards those who could not be healed or rehabilitated thanks to medicine. Hence also the concept of health was put under discussion: when a person with disability is observed as a person in health need, consequently she/he is considered as ill (14-16). This totalising interpretation of disability has given birth to a sequel of critics, which originate other and further interpretative models, still in discussion (17-19).

In addition to what said, moreover, it is interesting to note that the paradigm of the medical-individualistic model enshrines a transversal extent: it was also very popular in the so-called communist countries, where disability was viewed as a personal tragedy to be hidden when it could not be eliminated or cured. This is reflected by the large institutions that, until the early part of this century, held hundreds and hundreds of people throughout eastern Europe, institutionalised because they had an impairment that could not be medically treated or because of the medical treatments they needed. These people, who were necessarily left out of the economic mass production system, were useless to society and were therefore shut away in distant and miserable places (19). This situation continued for decades even after the fall of the communist regimes in eastern Europe and in many cases is still alive.

In the early years of the 1960s, the first activists for the rights of people with disabilities started their political fight to stop disability being viewed simply as a medical condition or an experience exclusively within the personal sphere, and for the introduction of basic concepts such as independence and self-determination. As said, up until then, everywhere disability was considered as a factor of individual health requiring only medical attention or health services. Current times asked to overcome the person with a disability viewed as someone suffering from a negative individuality, a personal tragedy, to be helped in some way, whose experience remained within the private, and therefore personal or individual, sphere.

Social instances and public demonstrations required to set aside the paternalistic or religious approach considering the person with a disability as needing help, compassion and pity, depersonalised in their individual person, which was reduced to the disability or impairment.

Things changed more with the birth of the activist movements and Disability Studies. The first upheavals in the fight for the rights of people with disabilities took place in English-speaking countries (US and UK): years and years of deprivation or discrimination (20) were finally cancelled after lengthy and extenuating battles for rights, protests and marches of all kinds and universally.

From and within these fights a new model of interpretation of disability was born, based on the social consideration of the disability prescinding from the health/medical point of view (21), and - willing or unwilling - its effects are still present in our societies and is influencing also those who remained and remains stick to the medical model.

Social model

Partly on the basis of the interpretation of a society that disables, the studies that began at the end of the 1970s and early 1980s evolved from the medical-individualistic paradigm and started to view disability within its social context, interpreting it as a social construction created by that context. Thanks to the movements for the rights of people with disabilities, as said, the model that would uproot the one previously described took shape in the 1970s. This was the aforementioned paradigm of the social model, interpretation of which has continued to evolve right up to the present day.

Along with this paradigm, disability represents a social construct, a process that denies participation in society and the recognition and respect of people with specific characteristics (based on prejudices of various kinds).

The existence of this preconception forms the basis of the social process of “becoming disabled”, which could be frustrated or prevented by altering the social context in which it is placed.

In other words: people are not disabled, they become disabled (9).

A clear theoretical distinction was made between impairment and disability. As above already hinted, impairment was defined as a functional limitation that a person may have as the result of an objective factor. Disability was interpreted as the loss or limitation of the personal or social possibilities of participating in society as a result of social or spatial barriers.

The invention of the expression “social model” is due to Mike Oliver. He did not invent the principles underlying the social model; they came out of the booklet published by the British *Union of the Physically Disabled against Segregation* (UPIAS) in 1976 (22). It was Oliver, however, who named it, after developing the idea as a tool to aid his students to understand the meaning of the model same. He explained:

> [The social model] was basically giving you the opportunity, both personally and politically, to rethink about yourself and your position in society (23).

It enshrined a reversal of perspective: it was not the person with a disability who was supposed to conform with society, by adapting, curing or concealing the disability, but rather society that was supposed to adapt to people with disabilities, removing the barriers it had itself created. Society had created disability, so society was supposed to eliminate it. As interpreted by Pilar Gomiz Pascual.

The context is what defines the “disabled” person, not the impairments or lack of ability of the individual. (4).

Consequently, a radical change in interpretation of the contribution the individual makes to society was being demanded. Up to that moment, the liberal and capitalist doctrine of western society together with the communist doctrine based on the capability to participate to the productive system ensured that people were assessed on the basis of the contribution they could make to society. According to the theory of Parsonian functionalism (24), each individual contributes to the dynamics of society to allow it to progress, in an interdependent and correlated manner. With shared objectives, society thus not only progresses, but also maintains its balance, as it remains within the pre-set standards and complies with the functionalist model. Each member of society is aware of their role and understands the objective they must pursue with their social activity.

With this interpretation, a person with a disability would immediately lose their place in society, as they would be unable to participate fully in the social activities, as the qualities of complete ability and state of health would not be reflected in them. Disability has been observed therefore as an impediment to the total achievement of society's objectives, a threat to order and a deplorable deviation.

The one theorised by Oliver was – and is – a different interpretative model of the entire social system, which no longer had a dominant and perfectly functioning group and minority groups excluded from it for any reason (not only as a result of the disability, but simply because they did not conform with the majority in terms of normality or illness). It was a new social construct that would lead to the end of the state of oppression in which people with disabilities had lived until then, subject to stigma and discrimination, exclusion and marginalisation, and move towards liberation, as clarified by Oliver:

> For me disabled people are defined in terms of three criteria; (i) they have an impairment; (ii) they experience oppression as a consequence; and (iii) they identify themselves as a disabled person. (25)

The social model was at the basis of the new born *Disability Studies*, which questioned the foundations of a functionalist society to obtain an interpretation of disability that would result in a constructionist vision of the social context. For the Disability Studies' scholars, society constitutes thus a social construct, an organism that learns and is created without an objective and established predetermination. Society is no more viewed as a passive being that simply perpetrates standards accepted as "normal", but adapts its own form to its members. This society is therefore constructed with and around persons with disabilities and not despite or without them, so it adapts to them from a functional standpoint.

By distinguishing impairment from the social condition, the first theoreticians and scholars of Disability Studies prepared an all-inclusive model of the theoretical and social framework of disability. The first theorists of this model were, as said, Mike Oliver and other scholars from the so-called School of Leeds and later from the UK, such as Colin Barnes, Vic Finkelstein, Tom Shakespeare, Len Barton, and others.

This new interpretation model viewed disability as a form of oppression caused not so much by the impairment, instead by the society in which the person lived. With its barriers, society works against those with an impairment that disables them - not the impairment itself - and that oppresses and stigmatises the person with a disability. Disability is a social construct that oppresses, segregates, stigmatises and separates and nota a medical issue.

The basic principle at the origin of the social model was the diverse concepts of impairment and disability deepened in the definition also given by UPIAS in "The Fundamental Principles of Disability" in 1976 (26), which:

> Impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

And then it concluded:

> Physical disability is therefore a particular form of social oppression (27).

This constitutes the basis of the most holistic and affirmed interpretation of disability and the condition of the person with a disability based on the social model and it was no longer just a personal event limited to the individual sphere or to the medical domain.

Personal is political was one of the slogans used by the activists of the movements of people with disabilities. The experience of the individual was a part of the society and therefore became a political fact and, as such, worthy of attention by the community, who could relegate anymore people to the margins of society, as a result of a personal fact.

And if *personal is political*, then decisions on people could not be taken without the active participation of the people to whom those decisions are referred.

Nothing about us without us was, in fact, another slogan that turned out to be famous, as it summarised the content of the protest so well.

This aphorism is the title of the book of James Charlton (28), who in 2000 published his "Nothing about us without us. Disability Oppression and Empowerment", and shortly became the motto of the whole disability rights movements protesting against oppression, defiance and absence of self-determination freedom and independent living. The concept of the book is that persons with disability know what is best for them and they should be asked.

It was no longer politics or society that could or should make decisions on the person with a disability, but there should be a transparent process in which all those affected by the decision participated, and people with a disability above all.

Cultural model, biopsychosocial model and evolutions

Current theories on persons with disabilities have changed over the years and evolved from the initial medical model to go through the social model towards new ones based on the last, thus not believing that considering society as the sole creator of disability of the individual was truly helpful in moving towards the necessary cultural and political paradigm shift.

Tom Shakespeare in his "Disability Rights and Wrongs" (29) said that "people are disabled by society and by their bodies" (8), thus confirming that disability cannot be approached simply as a social phenomenon prescinding from the possible medical aspect or solely as an impairment relating to the personal sphere. It is the joint presence of these two factors that disables a person with an impairment and prevents them from developing in all aspects: as a person, as a citizen, as a woman or as a man. In fact, one of the criticisms of the social model since its inception, which would lead to its review over the years, was its lack of focus on the medical impact of disability and an underestimation of its scope (30). According to some (4), however, the social model did not ignore at all the medical or biological aspect of a disability.

It was no coincidence that formulation of the social model was followed, over the years, by other interpretative paradigms. Doubts were immediately raised over analysis of the two prevailing paradigms (more on the medical-individualistic one and lesser on the social model), which appeared too focused on several specific and partial aspects, and disregarded the holistic approach to disability. As the years passed and the (also theoretical) concept of disability was examined in greater detail, it became clear that any narrative using theories and concepts based on a mono-dimensional interpretation – such as those adopted within the medical-individualistic and social paradigms – was inevitably partial in nature and, as such, destined for failure. It is no coincidence that, in relation to a disability "it is not possible to tell a single and exclusive story about something that is complex" (8).

The cultural model starts with the points just examined up to now and evolves towards a more open and comprehensive view of disability, moving away from the fixed points that forced the previous models into a corner. This paradigm has evolved from the feminist idea and is based on sociological approaches that also consider other aspects, which were perhaps or partially disregarded in the previous theoretical interpretations of disability.

The foundations of a society that attributes value to certain things and not to others are placed in doubt. Ableism is questioned, as it is the tendency to seek perfection and the obligation to be active and productive according to predefined standards, with an able body always at the centre. This is all considered within the framework of a cultural substratum, as a set that encompasses different but always unequal approaches to people who deviate from the norm, are not able-bodied or perfect. This results in them being stigmatised and discriminated against as "other" with respect to the "whole". Disability becomes a social category of analysis, a line of investigation, a different interpretative model, the outlet of which is Disability Studies. This is why disability becomes more an effect of relations of power than a fact in itself (31). Disability as a system of representation inserted in a social context but dictated by culture.

This means that factors not considered previously become important, such as language, race, gender, psychological and legal aspects. It is an approach to culture that attempts to uproot the cultural paradigms anchored to righteousness and discrimination, without focusing on and stopping at political, social and economic barriers, considered almost exclusively up until then.

People with disabilities are the first being asked to overcome the stigma and to go beyond the barriers that forced them into social isolation (8), by taking action themselves and actively participating in their own liberation from oppression, perhaps deciding whether to define themselves as disabled or not.

Several of these aspects are clearly outlined by Alessandra Fabbri in her autobiography. For example, she says:

> Personally, I hate the image of a handicapped person as a victim. Handicap, I want to emphasise once again, is not a synonym of inactivity, so - and I am being deliberately provocative here - I say, to myself above all "Get up and walk"… which does not mean use your legs, but take action!!!

The cultural paradigm, like the others, has both positive and negative aspects. From an objectively critical standpoint, it could be said that this approach, leaving aside the medical approach entirely is, in some ways, preferable to the social approach. But the paradigm in question currently remains more detached from reality, even though it represents a theoretical framework of criticism of a society and a culture that produces oppression and does not offer practical solutions that could help solve or remove stigma and discrimination. Although it provides drivers for a holistic interpretation of reality, it does not include single steps towards actual liberation, but suggests that it is individuals who must act, together or through the mechanisms of advocacy, to change the status quo. Hence it is not always simple for groups or individuals to achieve actual changes. However, it is certainly appreciable that people with a disability are considered to be the fulcrum of the action, who thus liberate themselves from a series of negative adjectives, ranging from ineptitude to inertia, abjection, passiveness, incapacity and others.

The biopsychosocial model has been developed taking into account the whole environment. It represents a biological, psychological and social approach arising from the reflection of an American psychiatrist, George Libman Engel (33), who elaborated his theory from the '70s and '80s of last century and then was borrowed by other scholars.

The basic idea of this model is that the state of health of a person is influenced by other equally important and essential factors, such those in the biological, psychological and social spheres.

It is another approach to health that is contemplating not the single issue or illness (34), but also and at the same time the boundary conditions of the interested person:

> The biopsychosocial model is both a philosophy of clinical care and a practical clinical guide. Philosophically, it is a way of understanding how suffering, disease, and illness are affected by multiple levels of organization, from the societal to the molecular. At the practical level, it is a way of understanding the patient's subjective experience as an essential contributor to accurate diagnosis, health outcomes, and humane care (35).

The biopsychosocial interpretative model lies within the more general intermediate paradigms, but a special room has been dedicated to it due to its acceptance. As a matter of fact, regarding the positive acceptance it encountered, there are four favourable points to be underlined. The first point is that this model was used by the World Health Organisation for its definition of the functional assessment parameters known as the ICF. Moreover, the second point is that this model recognises that disability is a status deriving from a complex set of factors, ranging from the biological to the mental sphere and the social factor, and this results - at least in theory - in a holistic approach to the individuality of the person and not a partial or reductive one. The third is that this model has been widely applied across the world, although in a strictly medical area. The fourth and last point is that Italian legislation has cited it in various laws over recent years and consequently it merits further examination.

In order to get away from a theoretical framework too closely anchored to constructivism, other interpretative models appeared over time and overlapped each other in part. The term "intermediate paradigm" is used to refer to what, in a certain sense, is a spurious grouping of interpretations that evolved from the rigidity of purely constructivist interpretations, even though they always disdained the exclusively medical approach.

Conclusions

In the ongoing and lively debate between functionalism and constructivism, the social models of interpretation of disability have often reflected and continue to reflect the times when they were implemented. But all the interpretative models that have followed each other over time have been united in their lack of appreciation of the medical-individualist model. The proposal of different theoretical and interpretative frameworks has been followed by discordant or similar discussions and narratives.

As time passed, it becomes increasingly clear that disability is not a single concept definable once and for all, but it is always required an approach that takes its multi-faceted nature into account.

In conclusion, it is worth to underline how the history of the conceptualisation of disability could affect present times and the current approach to disability even under the sole medical point of view, where the impairment has to be cured, healed or a rehabilitation path has to be offered. This can succeed with the full consideration of the impact of the illness or of the impairment in the life of the person with disability, who is no more considered a mere object of cure.

Times and fights produced a deeper awareness of disability as inserted in the social contest and which cannot be separated from the boundary conditions of the persons who have a disability.

A holistic approach to disability produces better results and the impairment and its cure is not to be studied as a separate factor in the life of a person. Therefore we can conclude that a dialogue among different discipline like medicine, biology, psychology, sociology and others could led to a better approach to persons with disability as a whole and not as the *ressemblement* of isolated instances to be examined in different and separate domains.

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