Social Model: A New Approach of the Disability Theme[1]

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The experience of disability is part of the daily lives of people who have a disease, lesion or corporal limitation. Disability is still understood as personal bad luck; moreover, from the social and political points of view, the disabled are seen as a minority. The aim of this study is to contribute to the knowledge about the experience of disability. The research presents a new approach on the theme: the social model. This approach appeared as an alternative to the medical model of disability, which sees the lesion as the primary cause of social inequality and of the disadvantages experienced by the disabled, ignoring the role of social structures in their oppression and marginalization. The study permits reflecting on how the difficulties and barriers society imposed on people considered different make disability a reality and portray social injustice and the vulnerability situation lived by excluded groups.

Descriptors: Disabled Persons; Bioethics; Vulnerability; Social Justice.

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Modelo social: uma nova abordagem para o tema deficiência

A experiência da deficiência faz parte da vida de pessoas que têm doença, lesão ou limitação corporal. A deficiência é compreendida, ainda, como um fato de má sorte pessoal e, do ponto de vista social e político, os deficientes são vistos como minoria. Este estudo pretende contribuir para o aprofundamento dos conhecimentos sobre o tema deficiência. A pesquisa traz nova abordagem do tema: o modelo social. Essa abordagem surgiu como alternativa ao modelo médico da deficiência, que reconhece na lesão, na doença ou na limitação física a causa primeira da desigualdade social e das desvantagens vivenciadas pelos deficientes, ignorando o papel da sociedade na sua opressão e marginalização. O estudo permitiu refletir como as dificuldades e barreiras impostas pela sociedade às pessoas, consideradas diferentes, tornam a deficiência uma realidade e retratam a injustiça social e a situação de vulnerabilidade vivida por grupos excluídos.

Descritores: Pessoas com Deficiência; Bioética; Vulnerabilidade; Justiça Social.

Modelo social: un nuevo abordaje para el tema deficiencia

La experiencia de la deficiencia hace parte de la vida de personas que tienen una enfermedad, lesión o limitación corporal. La deficiencia es comprendida, también, como un hecho de mala suerte personal y, del punto de vista social y político, los deficientes son vistos como una minoría. Este estudio pretende contribuir para profundizar los conocimientos sobre el tema deficiencia. La investigación trae un nuevo abordaje del tema: el modelo social. Ese abordaje surgió como una alternativa al modelo médico de la deficiencia, que reconoce en la lesión, en la enfermedad o en la limitación física la causa principal de la desigualdad social y de las desventajas experimentadas por los deficientes, ignorando el papel de la sociedad en su opresión y marginalización. El estudio permite reflexionar como las dificultades y barreras impuestas por la sociedad a las personas consideradas diferentes tornan la deficiencia una realidad y retratan la injusticia social y la situación de vulnerabilidad vivida por grupos excluidos.

Descriptores: Personas con Discapacidad; Bioética; Vulnerabilidad; Justicia Social.

Introduction

The experience of disability is part of the lives of people with an illness, injury or bodily limitation. Few studies have been done on this theme, however, and it receives little encouragement for research around the world, including in Brazil. Disability remains widely understood as a misfortune or bad personal luck[1] and, from the social and political viewpoint, the disabled are seen as a minority. Therefore, literature about the theme is practically non-existent.

In Brazil, research is concentrated in biomedicine, developmental psychology or special education. This research intends to contribute to deepen knowledge about disability. The paper presents a new approach towards the theme: the social model. According to this model, disability results from the disadvantages or restrictions provoked by social organization nowadays, with little or no consideration for people with physical lesions, who are excluded from society's main activities[2].

The social model of disability was structured in opposition to the medical disability model, which sees the lesion, illness or physical limitation as the primary cause of the social inequality and disadvantages the disabled experience, ignoring the role of social structures in their oppression and marginalization[3]. Between the social and the medical model, the difference lies in the causal logic of disability. According to the social model,

its cause lies in the social structure. For the medical model, then, it lies in the individual[4]. In summary, the basic idea of the social model is that disability should not be understood as an individual problem, but as a matter of life in society, which transfers the responsibility for the disadvantages of a person's bodily limitations to society's incapacity to foresee and adjust to diversity[5].

A deeper understanding about the theme can be of help in disabled people's family, occupational and social insertion and improve their quality of life*, justifying research in that area.

The concept

People with physical, sensory and cognitive alterations constituting a category called the disabled is a contemporaneous idea. Historically, the classification was developed according to people's physical or mental alterations. They were described as crippled, deaf, blind and mad. The disability concept was coined in the first half of the 20th century to characterize these people as a group[6].

This theme has received little attention, however. Disability needs to be better understood and disabled people need to be treated as human beings with rights and duties, as citizens. Likewise, society needs to discuss the theme and this discussion should reflect in public support policies for the disabled. This change starts with the understanding of what is defined as disability and how society can be responsible for it[7-8]. This debate faces many barriers, one of which is related to the terminology that has to be used when discussing the theme.

In health, education and even in the assessment criteria to receive public benefits, different definitions of disability are used. In general, disability presupposes that variations exist in some skills, qualified as restrictions or lesions. What does not exist however, is a consensus on what variations in skills and functionalities would characterize disabilities. Some people with lesions do not experience disability, while others with expected lesions consider themselves disabled. Drawing a border between these various expressions of human diversity is an intellectual exercise at the limit of different knowledge types, particularly between medical knowledge and social sciences. This range of interpretations and experiences regarding the body and its relation with the social environment spans a large part of contemporary discussions on disability and social justice[9].

The medical model is still hegemonic and addresses disability through a set of health care theories and practices, which presupposes a causal relation between the lesion or disease and the disability experience. In this model, disability is the expression of a person's bodily limitation for social interaction[9].

The disability idea is frequently related to limitations in what are considered basic skills for social life. However, it is not easy to determine what these skills are. In debates on the theme, they relate to mobility, communication, social interaction, cognition and use of the senses. Another condition to characterize a variation in skills as disability is that it is expressed in the body as a permanent or long-lasting state. Skills to perform different tasks are not equally distributed in the population, however. Defining the skill variation to be considered a lesion or a restriction is, at bottom, a value judgment. The fact is that, although most disability definitions are based on bodily variations qualified as lesions, the two concepts (lesions and disability) are not synonyms[9].

In the attempt to answer the need for further knowledge about the consequences of illnesses, in 1976, the World Health Organization (WHO) published the International Classification of Impairment, Disabilities and Handicaps (ICIDH)[10]. WHO's goals were to transpose the logic classification of the International Classification of Diseases (ICD) to the field of lesions and disability, so as to include the consequences of chronic and debilitating illnesses and systemize the biomedical language of lesions and disability[11]. According to this conceptual framework, impairment was described as loss or abnormality in bodily organs, systems and structures; disability was characterized as the consequence of impairment from a functional performance perspective, that is, the performance of essential activities of daily living; and handicap reflected individuals' adaptation to the environment, resulting from impairment and disability[10].

The ICIDH described the conditions deriving from the disease as a linear sequence: Disease → Impairment → Disability → Handicap[12]. The review process of the ICIDH appointed its main weaknesses: the lack of relation between the component dimensions and the fact of not addressing social and environmental aspects. Hence, after different versions and countless tests, in May 2001, the World Health Assembly approved the International Classification of Functioning Disability and Health[13]. The Portuguese version was translated by the Brazilian

WHO Collaborating Center with the title *Classificação Internacional de Funcionalidade, Incapacidade e Saúde* (CIF)[14].

The CIF describes functionality and disability related to health conditions. It identifies what people can or cannot do in their daily lives, in view of organ or bodily system and structure functions, as well as limitations to activities and social participation in the environment the people live in[15].

Differently from the ICIDH, which proposed the understanding of disability through a uni-causal disease-based model, the CIF model is multi-causal and functionality-based, covering the bodily function and structure, activity and social participation components. According to this model, disability result from the interaction between people's dysfunction, activity limitation, restrictions for social participation and environmental factors, which can act as facilitators or barriers for activity performance and participation[16].

Thus, the CIF is based on a biopsychosocial approach that incorporates health components at bodily and social levels. Consequently, in the assessment of a disabled person, the distinction between this and the biomedical model is based on the etiological diagnosis of the dysfunction, evolving to a model that incorporates the three dimensions: biomedical, psychological (individual dimension) and social. In this model, each level acts on and is influenced by the others, and all are influenced by environmental factors[16].

The pragmatic goal of the CIF is to provide a standardized language and a model to describe health and health-related conditions, permitting data comparisons among countries, health care services, as well as follow-up over time. The concepts presented in the classification, however, support a new paradigm to think and address disability and disablement: they do not only derive from health/disease conditions, but are also determined by the context of the physical and social environment, due to different cultural perceptions and attitudes towards disability, service availability and legislation[12]. The CIF reflects the idea that disability results from interaction between skills, abilities and the environment[13].

The change in WHO's approach resulted from disability communities' more than twenty-year-old advocacy. The ICIDH model received plenty of criticism by these groups and by experts who defended the social approach, as the disease was the starting point for the discussion about disability. In other words, a standard deviation was needed which society considers normal for the disability to exist[11]. Besides the pejorative foundations of the handicap concepts, which in English derives from the expression *cap in hand* and means that the disabled person had to ask for handouts to be able to survive[1].

The CIF proposes an assessment system that relates functioning with social contexts, demonstrating that a person can have injuries without being disabled (a spinal cord injured in an environment where wheelchairs can be used, for example). In this perspective, someone may expect lesions and be socially considered a disabled person (a diagnosis predictive of genetic disease for example). The classification is no longer based on consequences of an illness but, instead, it assesses health components[9].

The health and illness context was one of the starting points for the disability assessment in the CIF model, but the importance of other domains to understand this phenomenon was emphasized[17].

Experts affirm that the CIF can be used in many sector, include health, education, social security, occupational medicine, statistics, public policies, among others[12,15,18]. One of the advantages appointed for the adoption of the model is the possibility of uniformizing concepts, which permits communication among researchers, managers, health professionals, civil society organizations and users in general. One of the most explored fields for the application of the CIF has been the physical medicine and rehabilitation area, regarding follow-up of the health state for individuals under treatment. Applying the CIF in public health, however, can provide the base for broader and problem-solving policies and initiatives for the disabled population[12].

For some time, the use of the term disabled was avoided to refer to people experiencing disability. This term was considered to cause stigma. As an alternative, the terms people with special needs or people with disability were used to highlight the people's importance before the disability. People who prefer to use disability to acknowledge a person's identity use the term disabled. These people follow principles similar to the use of the term negro to refer to black or mulatto people[19], although the recognition of this identity, this biological reality, hides social functions and injustice underlying people's designation in this group[1].

According to Wendell*, the understanding of what constitutes disability varies. Officially accepted

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* Susan Wendell is a Canadian philosopher who developed a chronic illness, myalgic encephalitis, accompanied by intense pain and extreme fatigue. She explored and analyzed the disability experience in a very original way in her book *The Rejected Body: feminist philosophical reflections on disability*, published in 1996.

disability definitions (public entities and social services) are determined by the quantity of care these people receive. In the North American reality, this includes economic assistance, education, skills development and rehabilitation, obtaining equipment, domestic adaptations, hiring specialized care staff and even medical supplies. For unemployed disabled people, it includes food and housing. Assistance can also include special forms of transport or the sticker to park on a reserved place[1]. The definition of socially accepted disability determines disabled people's recognition by friends, family members and work colleagues. Recognition of the disability is important not only for the disabled to receive these people's help, but also for their own recognition and confirmation of reality, which is important to keep them socially and psychologically anchored in a community. Defining oneself as disabled affects a person's identity. People start to understand that they are not alone and belong to a group, but at the same time understand that they carry the stigma of belonging to that group[1].

According to Diniz*, disability should be understood as a broad and relational concept. Disability is any and all forms of disadvantage resulting from the body's relation with lesions and society. Lesion, in turn, covers chronic illnesses, deviations or traumas that, in the relation with the environment, imply restrictions in skills that are considered common for people of the same age and gender in each society[4].

Oliver** criticizes the person with disability concept, considering that this liberal and humanistic view is in line with reality as the disabled experience it, who sustain that disability is an essential part in the constitution of their identities and not merely an appendix. In that context, according to the author, it does not make sense to talk about people and disability separately, as the disabled demand acceptance as they are, that is, as disabled[5].

The disability definition is neither related to the lack of a limb, nor to decreased sight or hearing. It is characterized by the difficulties people with some physical or mental alteration experience to relate with or integrate into society[20]. Disability should not be considered a synonym of disease, as it is a social phenomenon that is more or less frequent based on a society's living conditions, its organization form, the

State's activity, respect for human rights and goods and services available for the population[21].

According to Omote[22], to understand disability, it is not enough to look at people who are considered disabled, seeking attributes or properties in their organism or behavior, which can be identified as the disability itself, or some correlate. Instead, one needs to look at the context in which someone is identified and treated as disabled, together with the belief and value system and the dynamics characteristic of negotiation. This context conditions the way disabled people are treated and are conditioned by the treatment.

In the terminological discussion about disability, two main trends can be identified: the American, based on a civil rights platform, which adopts the person with disability concept, and the British, based on the social model of disability, which prefers using the term disabled person or disabled[4].

In Brazilian Legislation (Law 7.853/1989; Decree 3.298/1999), the term person with disability is used, designated as "the person with limitation or incapacity to perform activities"[23]. The Law divides people with disabilities into the following categories: physical, hearing, visual, mental and multiple disabilities.

Research about disability

In the United Kingdom, disability studies are a solid research and teaching area, especially at British colleges. Disability studies are preferentially defined as research and actions at the interface between human and health sciences, with most researchers coming from the field of social sciences[7].

In Brazil, intellectual production on disability is practically non-existent. It is a new area for public health research and interventions. The idea of disability as a complex interaction between the body with a lesion and an environment that is hardly adequate for the body skill restrictions caused by the lesion turns the disability concept into something beyond the mere inequality caused by the bodily difference[4].

Until the second half of the 1990's, the medical model dominated disability definitions. Demographic surveys, which joined information about disability in Brazil since the end of the 19th century, and legal texts on the topic throughout the 20th century reflected the

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* Débora Diniz is a Brazilian anthropologist, faculty member at the University of Brasília and pioneer in disability studies in Brazil. Among other works, her book *O Que é Deficiência* (2007) stands out.
** Michel Oliver is a pioneering sociologist for the social model. He has been quadriplegic due to a spinal cord injury since 1962. Besides the books and papers mentioned here, he is the author of other works, among which the following stand out: Social Work with Disabled People (1983) and Walking into Darkness: The Experience of Spinal Injury (1988).

view that disability was defined by a specific set of body defects. Although this still happens, like in the definition of disabled adopted in Brazilian legislation, in some cases, a trend is verified to understand disability based on a new model, the social model, reflected in the modifications of data survey questionnaires for the 2000 Demographic Census and in the interpretation of laws on care for the disabled, for example[4,19].

The social model of disability

The social model is an approach that emerged in the United Kingdom in the 1960's and provoked upheaval in traditional disability models by withdrawing the origin of the inequality the disabled experience from the individual and return it to society. It is a theoretical and political current opposed to the dominant medical model[5].

The social model is a broad discussion about wellbeing and social justice policies for the disabled. The first experts on the model were disabled people, mostly men, institutionalized due to physical lesions, who were dissatisfied with the situation of oppression they were living in[3].

Arguments that originated the model basically boiled down to two aspects: the first was related to the fact that the body's injury neither determined nor explained the social and political phenomenon of disabled people's subalternity. Attributing the oppression disabled people are victims of to the loss of skills provoked by the lesion means mixing up lesion with disability. According to the experts, disability is a sociological phenomenon and lesion a biological expression. The meaning of lesion as disability is a strictly social process. In this line of reasoning, the explanation for a disabled person's low educational level or unemployment should not be sought in the restrictions provoked by the lesion, but in the social barriers limiting the expression of their abilities (potentials). Removing disability from the field of nature and its transfer to society was a revolutionary theoretical change[3].

The second argument appointed that, as disability is a sociological phenomenon and not determined by nature, the solution for the conflicts involved should not center on therapeutics, but on politics. The first social model theoreticians defined themselves against all individualizing explanations of disability. Disability should not be understood as an individual problem, a personal trajectory, but as a consequence of social arrangements hardly sensitive to diversity[3].

Through the adoption of the social model, disability is no longer a tragic problem that separately affects some poorer individuals, for whom the only appropriate social answer is medical treatment (medical model), but is addressed as a situation of collective discrimination and social oppression, for which the only appropriate answer is political action[24].

Changing the perspective did not mean, however, that social model theoreticians did not acknowledge the importance of biomedical advances to treat or improve disabled people's bodily wellbeing. Instead, new treatment techniques resulting from biomedical advances were welcome. Strong resistance existed, however, against the large-scale medicalization process the disabled were victims of. Due to the fact that they were dealing with a sociological phenomenon, according to the social model theoreticians, efforts should focus on modifying the structures that provoked or reinforced the disability, instead of just trying to cure, treat or eliminate the lesions or incapacities[5].

In the 1970's, the first organization of disabled people with eminently political and not just care objectives emerged, The Union of the Physically Impaired Against Segregation (UPIAS). Originally, the UPIAS proposed some definitions that expressed the effect of social exclusion on the production of disability: "Lesion is the partial or complete absence of a limb, organ or existence of a defective bodily mechanism; Disability is the disadvantage or activity restriction provoked by the contemporary social organization, with little or no consideration for people with physical lesions and excluding them from the main activities in social life"[2]. Through the emergence of the social model, the medical model's emphasis on physical limitations was reconsidered and, thus, a large debate started about the limitations of the vocabulary used to describe disability. The intent was to highlight that there did not necessarily exist a direct relation between lesion and disability, transposing the debate about health to the field of social and political organization. Lesion would be a bodily characteristic, similar to gender, skin color, while disability would be the result of the oppression and discrimination people suffer in function of a society organized in a way that does not permit their inclusion in daily life. A person may have an injury but not experience disability, depending on the extent to which society is adjusted to incorporate human diversity[19]. Jenny Morris*, exemplifying this fact,

*Jenny Morris is a writer and researcher in England. She is disabled and has participated in disability research since the start. She was one of the authors who demonstrated the particularities of disability among women and analyzed the reproductive experience of disabled women. Among her works, *Able lives: women's experience of paralysis* (1989) and *Independent lives? Community care and disabled people* (1993) should be mentioned.

argues that not being able to walk is an expression of the injury. Disability takes the form of the inaccessibility imposed on people who use a wheelchair[25]. The result of this review on the concepts' semantics was a radical separation between lesion and disability. The former represents the object of discussions about health, while the latter is a matter of society, rights and justice[19].

In general, the medical model demands great distancing of social standards of normality to consider a person as disabled. The criteria used to define disability are guided by the complete loss of certain organs or functions. Disability is identified by taking into account isolated characteristics of these organs and functions and comparing them with established limits for each of them. These criteria set the limits of disability for affected organs or functions, like minimal visual acuity, hearing ability levels, which can be assessed isolatedly, and also separated from the needs imposed by each person's social characteristics. The combination between the existence of a health condition below an abstract normality standard and the persistence of this condition over time allows the medical model to distinguish between disease and disability.

Thus, in the medical context, many illnesses are understood as temporary situations and, although some people are in worse health conditions according to normality criteria, these sick people are not considered disabled, because their decreased capacity is only temporary and does not permit defining an identity. In the medical approach, disability is an irreversible situation, a permanent condition. To give an example, being blind is a permanent condition for a person born blind, so that this person is considered disabled. People who cannot see due to a severe eye inflammation, on the other hand, are ill, as their situation is temporary[19].

In the social model logic, no distinction is made between illness and disability because it is considered that the adjustments society requires to cover human diversity do not depend on whether the person is ill or disabled, nor on how long this bodily condition will continue. If a person using a wheelchair to recover from a leg fracture needs the same transportation system adjustments as a person who is permanently unable to walk, why separate them in different groups?[3].

By not acknowledging that sick people also experience disability, the medical model excludes a large part of the population from care delivery by public policies. In fact, in Brazil, this part of the population has been historically excluded, as medical criteria were used in the disability definition social policy makers adopted in the 1980's and, until today, are still used[7].

The adoption of the social model entails the understanding that disability-oriented research and public policies cannot only concentrate on people's bodily aspects to identify the disability. Moreover, by distinguishing between disability and lesion, the social model opens room to show that, despite the range of lesions, there is a factor joining different disabled communities around a single political project: the experience of exclusion. All disabled people experience the disability as a social restriction, no matter whether these restrictions occur due to inaccessible environments, questionable notions of intelligence and social competence, the general population's inability to use sign language, lack of Braille material or hostile public attitudes by people without visible bodily lesions[5].

Final considerations

In Brazil, the living conditions of disabled people are practically unknown, as most of them still live in the private context, locked up in their homes or institutions. The society and the State know little about the needs and difficulties these people face.

The researchers hope that the knowledge resulting from this study permits further understanding about disability. Likewise, this study can add up to the voices that, even if timid, attempt to expose these people's condition of inequality, but not inferiority. Subjects who differ in their appearance, ability, in the way they think and see life but, at bottom, human beings like everyone else, with the same rights and duties. They also hope that this research will be yet another tool that provokes changes in the way of thinking and face disability in Brazil.

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