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ABSTRACT

This paper aims to demonstrate how the field of disability studies consolidated the concept of disability as social oppression. By reviewing the main ideas of the social model of disability, this article presents the genesis of the concept of disability as a restriction of participation for disabled people, as adopted by the United Nations Convention on the Rights of Persons with Disabilities, which Brazil ratified in 2008.

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KEYWORDS

Disability – Social model of disability – Medical model of disability – Convention on the rights of persons with disabilities.



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DISABILITY, HUMAN RIGHTS AND JUSTICE*

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1 Introduction

To inhabit a body with physical, intellectual or sensory impairment is one of the many ways of existing in the world. Among the narratives of inequality that are expressed in the body, disability studies appeared as the late comers in the humanities and social sciences. Heirs to gender studies, feminists and anti-racists, the social model of disability proposed a redefinition of the meaning of living in a body that had been considered, for a long time, abnormal (DINIZ, 2007, p. 9). As for sexism or racism, this new expression of oppression led to the creation of a neologism: *disablism* (DINIZ, 2007, p. 9). Disablism is a result of the culture of normality, in which the impairments are the target of oppression and discrimination (inserir nota 2). Normality, which can either be understood as a biomedical expectation of standard functioning for the species or as a moral precept for productivity and adaptation to social norms, was challenged by the understanding that disability is not only a biomedical concept but a political one as well. Disability expresses the oppression of the body with impairments: the concept of a disabled body or person with disabilities should be understood in political terms and no longer strictly in biomedical terms.

This change of the body with impairments from a medical problem to disability as oppression is challenging for the establishment of public and social policies (DINIZ, 2007, p. 11) inserir nota 3. Disability is not limited to a list of diseases and impairments that come from biomedical knowledge (DINIZ *et al.*, 2009, p. 21). Disability is now considered to be the patterns of inequality that are imposed by environments with barriers on a body with impairments. Therefore, the United Nations Convention on the Rights of Persons with

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Disabilities refers to participation as a parameter for the formulation of policies aimed at this population, defining people with disabilities as “those who have physical, intellectual or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society with others” (UNITED NATIONS [UN], 2006a, Article 1). Disability is not only what medical discourse describes but specifically the restriction of participation caused by social barriers.

Brazil signed the Convention on the Rights of Persons with Disabilities in 2008. This means a new concept of disability must guide political actions to ensure justice for this population. According to the 2000 Census, 14.5% of Brazilians are living with disabilities (BRAZILIAN INSTITUTE OF GEOGRAPHY AND STATISTICS [IBGE], 2000). The criteria used by the 2000 Census to calculate the size of the population with disability were markedly biomedical, such as difficulty in seeing, hearing, or moving. This is due not only to the biomedical model currently in force in the planning and management of public policies for this population in Brazil but mainly due to the difficulty of measuring what is considered *participation restriction* by the interaction between the body and the social environment.

The Convention on the Rights of Persons with Disabilities does not ignore the body, as it states “impairments of a physical, intellectual or sensory nature” (UN, 2006a, Article 1). It is the interaction between the impairments and the social barriers that restrict people’s effective participation. According to the Convention, the new understanding of disability should not ignore the bodily impairments, nor is it restricted to listing them. This redefinition of disability as a combination of a biomedical framework, which lists bodily impairments, and a human rights perspective, which denounces this type of oppression, was not a creation of the United Nations alone. For over four decades, the so-called social model of disability provoked the international political and academic debate on the failure of the biomedical concept of disability to promote equality between disabled and non-disabled people (BARTON, 1998, p. 25; BARNES *et al*, 2002, p. 4).

The biomedical model of disability claims that there is a causal relationship between the impairments and the social disadvantages experienced by people with disabilities. This thesis was challenged by the social model, which not only challenged the medical power over bodily impairments but also showed how the body is not a destiny of exclusion (BARNES *et al*, 2002 p. 9; TREMAINE, 2002 p. 34). The social meaning attributed to these impairments is that they are a natural disadvantage, which historically meant that bodily impairments were seen as bad luck or personal tragedy (BARNES *et al*, 2002, p. 6). If in the 19th century the biomedical model was a kind of redemption from religious narratives, which described impairments as the result of sin or divine wrath, today it is the biomedical authority which is being challenged by the social model of disability (FOUCAULT, 2004, p. 18). The criticism of medicalization suggests the inadequacy of the biomedical discourse to evaluate the participation constraints imposed by social environments with barriers. Therefore, for the United Nations Convention on the Rights of Persons with Disabilities, the disadvantage is not inherent to the body, but the result of values, attitudes and practices that discriminate against disabled people (DINIZ *et al*, 2009, p. 21).

This paper demonstrates how disability studies reinforced the understanding of

disability as a social disadvantage, challenging the biomedical narrative about what is normal and pathological. Through a historical review of the main ideas of the social model of disability, the article draws a picture of the concept of disability as a restriction on participation. This was the concept adopted by the United Nations Convention on the Rights of Persons with Disabilities, which was ratified by Brazil in 2008.

2 Disabilities and Impairments

There are at least two ways of understanding disability. The first way understands it as an expression of human diversity. A body with impairments belongs to someone who experiences impairments of a physical, intellectual, or sensory nature. But the social barriers are the ones that, by ignoring the bodies with impairments, force the experience of inequality. Oppression is not an attribute of the impairment itself but the result of non-inclusive societies. The second way of understanding disability claims that it is a natural disadvantage, and efforts should be focused on repairing the impairments in order to ensure that all people can operate in a typical pattern for the species. In this interpretative process, bodily impairments are classified as undesirable and not simply as a neutral expression of human diversity, as one must understand racial, generational, or gender diversity. The body with impairments should undergo a metamorphosis to normality, be it through rehabilitation, genetics, or educational practices. These two narratives are not mutually exclusive, although they point to different perspectives regarding the challenge posed by disability and human rights.

For the social model of disability, ensuring equality between people with and without disability should not be reduced to the supply of goods and biomedical services: as with racial, generational or gender issues, disability is essentially a human rights issue (DINIZ, 2007, p. 79). Human rights have an important claim to universal validity, which is to return the responsibility for the inequalities to oppressive social constructions (SEN, 2004). This means that impairments acquire meaning only when converted into experiences through social interaction. Not everyone with impairments experiences discrimination, oppression, or inequality, because it is the relationship between the body and the society which produces disability (DINIZ, 2007, p. 23). The greater the social barriers, the greater the participation constraints imposed on disabled people.

For the biomedical model of disability, a body with impairments should be the object of biomedical knowledge intervention. Impairments are classified by medical narratives, which describe them as natural and undesirable disadvantages. Rehabilitation practices or healing are offered and even imposed on bodies in order to reverse or mitigate the signs of abnormality. The result is that the closer to the simulacra of normality, the greater the success of the medicalization of impairments (THOMAS, 2002, p. 41). Educational practices comprise another universe for the taming of bodies: the controversy over oralist or manualist practices for deaf children is an example of different perspectives regarding how the deaf shall dwell in non-bilingual societies (LANE, 1997, p. 154). This was actually a controversy covered by the Convention on the Rights of Persons with Disabilities, which recognizes the “facilitation of learning sign language and promotion of the linguistic identity of the deaf community” (UN, 2006a, article 24, 3b).

Disability has been understood as a personal or family destiny according to religious explanations, which was understood either as misfortune or as a blessing in almost all societies (LAKSHMI, 2008). The challenge of the mystical and religious narrative by the biomedical narrative was received as an important step towards ensuring equality (BARTON, 1998, p. 23; COURTINE, 2006, p. 305). The origins of the barriers were no longer sin, guilt, or bad luck but genetics, embryology, degenerative diseases, traffic accidents, or aging. The biomedical narrative marked the dichotomy between normal and pathological since the impairments are only defined when contrasted with an ideal of the body without them. The challenge now is to refute the description of a body with impairments as abnormal. Abnormality is an aesthetic judgment and, therefore, a moral value on life styles, not the result of a universal and absolute catalog about bodies (DINIZ, 2007, p. 23).

3 The Genesis of the Social Model

One of the early attempts to bring disability close to the culture of human rights was made in England in the 1970's (UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION [UPIAS], 1976). The first generation of scholars defending the social model of disability was inspired by historical materialism and sought to explain oppression through the core values of capitalism, such as ideas of productive and functional bodies (DINIZ, 2007, p. 23). Bodies with impairments would be useless to the productive rationale in an economic structure that is not open to diversity. The biomedical model, on the other hand, indicated that the experience of segregation, unemployment, low education, among many other expressions of inequality, was caused by the inability of the body with impairments to do productive work. Today, the centrality of historical materialism is considered insufficient to explain the challenges imposed by disability in environments with barriers, but one must recognize the originality of this first movement to empower the social model of disability (CORKER, SHAKESPEARE, 2002, p. 3).

Other approaches emerged in disability studies, but the social model has remained hegemonic. The feminist and phenomenological approaches gained ground in the debate, expanding the narratives about the meanings of disability in cultures of normality (CORKER, SHAKESPEARE, 2002, p. 10). This was how impairments came to be described as neutral bodily attributes, and disability has summarized the oppression and discrimination suffered by people living with impairments in environments with barriers. By resisting the reduction of disability simply to impairments, the social model of disability offered new tools for social transformation and the guarantee of rights. It was not biology that oppressed but the culture of normality, which described some bodies as undesirable.

This change of interpretation on disability, shifting from the inequality of the body to social structures, had two implications. The first was to undermine the authority of the corrective resources that biomedicine commonly offered as the only alternative for the well-being of people with disabilities. Disabled people could not deny the benefits of biomedical goods and services, but they could challenge the supremacy that healing and rehabilitation had attained, implying the idea that the body with impairments is abnormal and pathological (CANGUILHEM, 1995, p. 56).

The second implication was that the social model opened analytical possibilities for a new description of the meaning of living in a body with impairments. The private experience of being in a body with impairments caused a limited scope of care in the household, often condemning those with greater dependence to abandonment and institutionalization. By exposing the oppression of social structures, the social model showed that impairments are one of many ways of experiencing the body.

The central thesis of the social model has enabled a shift of disability from private to public spaces. Disability is not only a matter of privacy and family care but a matter of justice (NUSSBAUM, 2007, p. 35). This symbolic passage from the *domestic* to the *public* shook several biomedical assumptions about disability. It has been stated, for example, that disability is not abnormal, not being limited to stigma or shame because of difference. The critique of the biomedical model does not mean ignoring how technology ensures people's well being (DINIZ, MEDEIROS, 2004a, 1155). People with bodily impairments experience pain, get sick, and some need permanent care (KITTY, 1998, p. 9). However goods and services are biomedical responses to health needs and are, therefore, universal demands. Unlike non-disabled people, impairments comprise lifestyles for those who experience them. Therefore, there are social model theorists that explore the idea of disability as an identity or community, like cultural identities (LANE, 1997, p. 160).

With the social model, disability came to be understood as an experience of inequality shared by people with different types of impairments: not the blind, deaf, or people in wheelchairs in their particularities, but disabled people, discriminated and oppressed by the culture of normality. Just as there are a variety of bodies, there are a variety of ways to inhabit a body with impairments. It was by bringing the studies of disability and cultural studies together that the concept of oppression won argumentative legitimacy: despite the ontological differences imposed by each impairment of physical, intellectual, or sensory nature, the experience of living in a body with impairment is discriminated against by the culture of normality. The dichotomy normal and pathological, represented by the opposition of the body with and without impairments, opened way for a new strategy for political intervention, as envisaged by the Convention on the Rights of Persons with Disabilities (UN, 2006a). In addition to other forms of discrimination, the concept of discrimination in the Convention includes the denial of reasonable accommodation, which demonstrates the recognition of barriers as a preventable cause of inequalities experienced by disabled people.

The social model originally claimed that a body with impairments would not be able to endure the capitalistic system (BARTON, OLIVER, 1997). The centrality of the social model as a critique against capitalism was substituted by cultural studies, which distanced disability even more from biomedical authority over the body. It is also the culture of normality which oppresses the body with impairment and not only the economy (DINIZ, 2007, p. 77). Social model theorists have offered evidence that to inhabit a body with impairments does not necessarily mean a sentence of segregation (YOUNG, 1990, p. 215). In the last two decades, the growth of population studies on aging strengthened the argumentative strategy of the social model of disability as a human rights issue: a body with impairments is a shared experience with aging (WENDELL, 2001, p. 21; DINIZ, MEDEIROS, 2004b, 110).

4 The World Health Organization and the Social Model of Disability

The World Health Organization (WHO) has two classification references for describing the health conditions of individuals: the International Statistical Classification of Diseases and Related Health Problems, which is the tenth revision of the International Classification of Diseases (ICD-10) and the International Classification of Functioning, Disability and Health (ICF). The ICF was approved in 2001 and anticipates the main political challenge of the definition of disability proposed by the Convention on the Rights of Persons with Disabilities: the document establishes criteria for measuring the barriers and restriction of social participation. Until the publication of the ICF, the WHO had adopted strictly biomedical language for the classification of bodily impairments, which is why the document is considered a milestone in the legitimization of the social model in the field of public health and human rights (DINIZ, 2007, p. 53).

The shift from the biomedical model to the social model of disability was the result of an extensive debate in the consultative stages of the ICF. The document that preceded it, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), assumed a causal link between impairments, disabilities, and handicaps (WHO, 1980). In this interpretative model of disability, a body with impairments would experience restrictions that led to social disadvantage. The disadvantage would be the result of impairments; therefore, the emphasis was on models of healing or rehabilitation. For nearly 30 years, the biomedical model of disability was sovereign in the actions of the WHO, which meant the hegemony of a language focused on the rehabilitation or cure of impairments in public policies in several countries. In Brazil, the biomedical model is used in population research, healthcare, and, in large part, education and health policies for people with disabilities (FARIAS; BUCHALLA, 2005, p. 192).

The vocabulary proposed by the ICIDH in 1980 was widely criticized by the emerging disability studies (WHO, 1980). There were different levels in the debate, but one was particularly embodied by the text of the Convention on the Rights of Persons with Disabilities: linguistic sensitivity towards the description of disability as a human rights issue, not just a biomedical one. As in studies of race and gender, biology and culture impose a permanent pendulum between what is defined as the fate of the body or the social oppression of the body. In feminist studies, the dichotomy between nature and culture was deconstructed in its own terms; the constitutive nature of sex to explain the existence of gender was ignored: sex and gender are interchangeable categories for the analysis of sexism (BUTLER, 2003, p. 25).

A similar analytic turn was triggered in disability studies to face *disablism*, the ideology that oppresses a body with impairments. The first generation of the social model sustained that the body should be ignored, as its emergence would facilitate the biomedical understanding of disability as a personal tragedy (DINIZ, 2007, p. 43). Adopting this posture, the study of aspects of the body with impairments, such as pain, addiction, dependency, or weaknesses would be to surrender to the concept of biomedical control of disability as a deviation or abnormality (WENDELL, 1996,

p. 117, MORRIS, 2001, p. 9). The result was the silencing of the body as an instance of habitability, and as a locus in which to describe disabilities. The semblance of normality for all bodies set the tone of the debates and political struggles of the 1970s for the social model.

But the silence was challenged by the emergence of other perspectives into the social model, especially feminism. Not coincidentally, the social model of disability began with white adult men in wheelchairs (DINIZ, 2007, p. 60), a group of people for whom social barriers would be essentially physical. The inclusion of this group would not subvert the social order, as in their specific case the simulacrum of normality was effective to demonstrate the success of inclusion. Even today road signs and public representations of disability indicate someone in a wheelchair as the icon. The metonymy of disability by the wheelchair should not be underestimated in a culture of normality filled with barriers to social participation for people with other impairments, for whom these barriers are not only physical.

The first feminists working in the social model launched the issue of intellectual impairments and care to the center of the discussions (KITTAI, 1998, p. 29). To seriously consider the diversity of impairments was not resolved with the simulacrum of normality; it was necessary to challenge the culture of normality. Social barriers for the inclusion of a person with severe intellectual impairments are multiple, difficult to measure, and permeate all spheres of public life. This is how the narratives about the body with impairments and the theme of care as a human need came to be discussed in disability studies. However, to consider care as a human need is also to bring the issue of disability closer to gender and family studies. The issue of gender equality serves as a background for the Convention on the Rights of Persons with Disabilities, from the preamble to the specific sections on the protection of girls and women with disabilities, and the role of families of people with disabilities (UN, 2006a).

The ICF, thus, was born after a long process of reflection on the potential and limits of biomedical and social models of disability. In a position of dialogue between the two models, the proposal of the document is to launch a bio-psychosocial vocabulary to describe disability. Despite the diversity of experiences of people with impairments related both to the body and to society, the ICF has universal ambitions (THE WORLD HEALTH ORGANIZATIONS' COLLABORATING CENTER FOR THE FAMILY OF INTERNATIONAL CLASSIFICATIONS, 2003, p. 18). This universal claim can be understood in two ways. First as recognition of the political force of the social model of disability for the revision of the document: from a classification of abnormal bodies (ICIDH) to a complex evaluation of the relationship between the individual and society (CIF). A disabled person is not simply a body with impairments but a person with impairments living in an environment with barriers. The second way of understanding the universal ambition of the ICF is also a result of the social model: the body with impairments is not a personal tragedy, but a life condition for those who experience the benefits of biotechnology and aging. Old age and disability are concepts brought closer together by the CIF and the new generation of disability theorists (DINIZ, 2007, p. 70).

But while progressing from the ICIDH towards the ICF, one of the most sensitive issues was how to describe disability. The same challenge was present in the elaboration

of the Convention on the Rights of Persons with Disabilities. The ICIDH used the concepts of impairments, disabilities, and handicaps. The demand from the social model of disability was to describe impairments as a neutral expression of the diversity of the human body, understanding the body as an instance of individual habitability – therefore, diverse in its condition. The vocabulary proposed by the ICIDH classified physical diversity as a result of diseases or abnormalities, besides considering that the disadvantages were caused by the inability of the impaired body to adapt to social life.

The revision of the ICF tried to resolve this controversy by incorporating the main criticisms of the social model (THE WORLD HEALTH ORGANIZATIONS' COLLABORATING CENTER FOR THE FAMILY OF INTERNATIONAL CLASSIFICATIONS, 2003, p. 32). According to this new vocabulary, disability is an umbrella term that embraces the body with impairments, activity limitations, or participation restrictions. This means that disability is not limited to impairments; it is the negative outcome of the insertion of a body with impairments into social environments that are insensitive to people's physical diversity. There is no primordial meaning in the body, so any attempt to reduce it to a certain fate must be ignored. This redefinition conformed to the critique proposed by the social model: disability is a cultural experience and not just the result of a biomedical diagnosis of abnormalities. It was also this spirit that has abandoned the notion of "handicap", especially because of its etymology which referred to disabled people as beggars ("cap in hand") (DINIZ, 2007, p. 35).

The Convention on the Rights of Persons with Disabilities has proposed a concept of disability that recognizes the experience of oppression suffered by disabled people. The new approach overcomes the idea of impairment as synonymous for people with disabilities, recognizing the restriction of participation as being the main aspect that causes the disability to be perceived as inequality. The importance of the Convention is to constitute a document of reference for the protection of the rights of disabled people in countries around the world. In all the signatory countries, the Convention is taken as the basis for the construction of social policies regarding the identification of both the subject of social protection as well as the rights to be guaranteed. The ICF, in turn, provides objective tools for the identification of the different expressions of *disablism*, enabling better targeting of policies.

5 Final Considerations

The recognition of the body with impairments as an expression of human diversity is recent and still a challenge for democratic societies and public policies. The history of the medicalization and normalization of disabled bodies by biomedical and religious knowledge superimposed a history of segregating people in long-term institutions. Only recently were the demands of these people recognized as a human rights issue. The United Nations Convention on the Rights of Persons with Disabilities established a new framework for understanding disability (UN, 2006a). Ensuring decent life no longer limits itself solely to the provision of goods and health care services, but also requires the removal of barriers and the guarantee of a social environment that is accessible to all people with physical, intellectual, or sensory impairments.

The social disadvantage experienced by disabled people is not a sentence of nature

but the result of disablism, which describes bodily impairments as abject to social life. The social model of disability challenged the narratives of misfortune and personal tragedy that confined disabled people to the domestic space of secrecy and guilt. The social model not only proposed a new concept of disability in dialogue with theories of inequality and oppression, but also revolutionized the way of identifying the body and how it relates to societies. The International Classification of Functioning, Disability and Health (ICF) of the World Health Organization has proposed a vocabulary for the identification of persons with disabilities in order to guide public policies in each country. Since 2007, the ICF has been adopted in the Brazilian legislation for the implementation of the Continuous Cash Transfer Program (CCT), a welfare income transfer to the disabled and poor elderly. The trend is that the ICF is being used in the identification of disability for social welfare policy as well as in all other Brazilian public policies.

The adoption of the Convention on the Rights of Persons with Disabilities recognizes the issue of disability as a question of justice, human rights, and promoting equality. The Convention was ratified in 2008, which will require the revision of infra-constitutional laws and establishing new bases for the formulation of public policies for the disabled population. One of the requirements of the Convention is the immediate review of all laws and state actions related to the population with disabilities. Compliance with this measure will bring direct results to guarantee the well being and promotion of dignity for people with disabilities in Brazil.

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RESUMOS

O objetivo deste artigo é demonstrar como o campo dos estudos sobre deficiência consolidou o conceito de deficiência como desvantagem social. Por meio de uma revisão das principais idéias do modelo social da deficiência, o artigo traça uma gênese do conceito de deficiência como restrição de participação ao corpo com impedimentos, tal como adotado pela Convenção sobre os Direitos das Pessoas com Deficiência da Organização das Nações Unidas, ratificada pelo Brasil em 2008.

PALAVRAS-CHAVE

Deficiência – Modelo social da deficiência – Modelo biomédico da deficiência – Convenção sobre os direitos das pessoas com deficiência.

RESUMEN

El objetivo de este artículo es demostrar cómo el campo de los estudios sobre discapacidad ha consolidado el concepto de discapacidad como desventaja social. Por medio de una revisión de las principales ideas del modelo social de la discapacidad, el artículo traza una génesis del concepto de discapacidad como restricción de participación al cuerpo con deficiencias, tal como adoptado por la Convención sobre los Derechos de las Personas con Discapacidad de la Organización de las Naciones Unidas, ratificada por Brasil en 2008.

PALABRAS-CLAVE

Discapacidad – Modelo social de la discapacidad – Modelo biomédico de la discapacidad – Convención sobre los derechos de las personas con discapacidad.