

Disability and medical inspection: the outline of the body

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Abstract

This article analyses how biomedicine evaluates the disabled body in determining the inclusion of a person with disabilities in Brazilian social protection system. An empirical research was conducted with 58 people who tried to have access to Continuous Cash Benefit Program (BPC), a social protection policy for impoverished disabled people. In order to have access to BPC, a disabled person undergoes a medical examination by physicians from Social Security National Institute (INSS), in which labor incapacity and the dependency are attested. Based on the cases that had or did not have access to BPC, this article explores the thin line between biomedical knowledge and moral beliefs about the normal and productive body.

Keywords

disability; medical examination; body; social assistance

Introduction

A disabled body is the expression of human diversity.¹ According to the 2000 Census, 14.5% of the Brazilian population presents functionality restrictions that may be characterized as a disability (BRASIL, 2000). But between body restrictions and an experience of disability there is a gap imposed by inequality. Inhabiting a disabled body is living with a body socially marked by stigma, social disadvantage or esthetic rejection (BUTLER,

2003). Social disadvantage imposed by disability is not nature's determination, but an expression of oppression by bodies considered normal. This argumentative spin from disability as a personal tragedy to disability as a matter of social justice was what allowed the displacement from the debate of biomedical knowledge to social knowledge (BARNES et al., 2002).

The understanding that disability is one of many ways to dwell in a body, possibly even being considered

a pride because of the difference, as happens with deaf communities, is still a challenge for biomedical knowledge (LANE, 1997; DINIZ, 2007). A deaf person is not someone who dwells in a body with hearing restrictions, but someone who lives in a society that discriminates other forms of communication that is not oralism (DINIZ, 2003). The individual's affirmation happens through the expression of the disabled body and no longer by denying the lesions, bringing together disability studies and cultural, feminist and anti-racist studies (CORKER et al., 2004). This doesn't mean abandoning assistance, cure or rehabilitation strategies provided by biomedicine, but revealing its insufficient character in promoting equality in unfair environments. The new field of disability studies, in which ideas from the social model have taken lead, is one of the most vigorous responses to this argumentative spin on disability as bad luck to disability as social oppression by the body (BARNES et al., 2002).

For the disability social model, the body is a privileged space where discriminatory discourses act, be it race, sex, gender, nationality, age or disability (BARTON, 1998). Inequality because of disability cannot be resumed to variations imposed by the body with lesions, but is expressed by the interaction with the social world which considers very little body diversity. The existence of a body as an outline of human habitability is not denied, but it is no longer enough to explain social exclusion of the disabled based on their body. In this new model to understand disability, oppression is no longer caused by the outlines of the body, but by values, attitudes and practices that discriminate disability.

This change in the perspective on disability challenges the limits of theoretical models on fairness (NUSSBAUM, 2007). There are body configurations in disability for which slight changes in transportation systems or work regimes would facilitate social inclusion (PIRES, 2009). However, there are cases of disabled people, particularly with mental disabilities, for whom affirmative actions will not be enough to promote dignity and equality: the challenge is admitting social protection to disabled people as a matter of justice (KITTAY, 1999; NUSSBAUM, 2007). It was under this sign of justice that the Federal Constitution of 1988 incorporated social protection to disabled people as a guarantee, in a new understanding of social assistance in Brazil. The Continuous Cash Benefit (BPC) is a social assistance policy that guarantees a monthly income transference that amounts to a minimum wage for the elderly and the poor people with disabilities (BRASIL, 2009).

BPC was regulated by the Fundamental Social Assistance Law (LOAS), from 1993 and implemented in 1996. In March 2009, it reached more than 2.9 million people, of which more than 1.5 million were disabled (BRASIL, 2009). The BPC design was changed from its initial plan in the 80's to its regulation by LOAS (BOSCHETTI, 2006). Even though the benefit does not demand compensations, the disabled person should be incapable of working and poor in order to be eligible

(ACRE, 2007; BRASIL, 2008).² Access to the benefit is guaranteed by medical and social assessments every two years: social inspection seeks to assert that the disabled person lives on a monthly income below 1/4 of a minimum wage and medical inspection must attest that the body is incapable to work and to have an independent life. Both inspections overlap in describing the body to be recognized as an object of State protection.

However, one of the most controversial topics about BPC is the eligibility of disabled people: which diseases, lesions, disabilities or outlines of the body should be eligible to social protection? How does the negotiation between biomedical and social knowledge happen to determine which body is disabled and deserves such protection? It is not enough to inhabit a disabled body and live under a poverty regime; the medical inspection report has the final authority on the eligibility of the benefit (MEDEIROS et al., 2006; SANTOS, 2006; DINIZ et al., 2007a; PENALVA et al., 2009).

This article discusses how the biomedical discourse evaluates the disabled body in order to grant the benefit. To receive the BPC, a disabled person is submitted to a body inspection conducted by physicians from the National Institute of Social Security (INSS). The disability must have already been diagnosed by another professional before the arrival at the INSS medical inspection center so that it may be evaluated according to the BPC access criteria. By means of an empirical study conducted at an INSS agency, the article examines the fine line that separates the biomedical knowledge and the moral conceptions on the normal and productive body.

Development of the research

The research was conducted in Unaí, a municipal INSS agency where medical inspections on disabilities are carried out. Unaí is a town in the countryside of Minas Gerais, with a population of a little less than 80 thousand inhabitants and a single INSS center. The data survey was performed by means of semi-structured interviews with three doctors, which is the total number of INSS medical inspectors in town and 58 disabled people who were seeking the BPC. All the BPC requirement processes filed by disabled people from 2004 to 2005 in town were also analyzed: 430 processes in total, 276 requests were denied (64%) and 154 benefits were granted (36%). The interviews with physicians were conducted in the INSS agency, while the interviews with disabled people were conducted in each of their homes.

The 58 participants were divided in two groups: people who received the benefit after social and medical inspections and people who had their request denied either because of the social inspection or because of the medical one. Of the 28 requests refused, 19 had medical reasons and 9 had income above 1/4 of a minimum wage *per capita* in the family. The total of participants equaled 10% of disabled people who had their access to BPC denied and 20% of disabled people who had their benefit granted from 2004 to 2005 in Unaí, according to data from the Ministry of Social Development and the

Fight against Hunger (BRASIL, 2009). The interviews were carried out in 2007 and the data transcribed and analyzed in 2008.

This research project was submitted to the Research Ethics Committee at the Human Sciences Institute at the University of Brasilia before the conduction of interviews. The research did not place any risks and the identity of participants was kept secret. Only people who understood the study procedures and accepted to take part were interviewed, after registering the free and aware consent term. Different phases of this research were financed by the Science Initiation Program of University of Brasilia (PIC/UnB), by the Equipment Edict of the Scientific and Technologic Enterprise Foundation (Finatec), by the National Health Fund (FNS) and Research Support Foundation (FAP) of the Federal District.

Biomedicine and work: the outline of the body

Inhabiting a disabled body is a condition to have access to the benefit. However, it is not enough to declare one's own experience of restricted functionality or impoverished life, it is necessary to have an opinion from a social and medical inspection to guarantee eligibility to BPC. This is not an easy classification, even for the biomedical discourse, which believes to be more objective than the social discourse: in 12 years of operation of the BPC, five different biomedical concepts for disability have been used (BRASIL, 2007a). As the concept is changed, the profile of the eligible group and the idea of who is disabled are altered for social protection. Unlike the income criteria, whose controversy is largely circumscribed to debates in court (SANTOS, 2006; PENALVA et al., 2009), the disability concept was legally changed in the last decade. The incorporation of the International Classification of Functioning, Disability and Health (ICF) terminology of the World Health Organization (WHO) (ICF, 2003) will bring new changes to the policy design as of 2009.

LOAS specifies article 203 of the Federal Constitution, which determines the BPC to "disabled people who can prove not having means to provide one's own maintenance or being supported by one's family, according to the law" (BRASIL, 1988). For LOAS, disabled people eligible to assistance benefits are those incapable to work and to have an independent life (BRASIL, 1993, 2007b). But what does it mean to evaluate disability by work incapability in order to grant a benefit? The choice seems to be an attempt to give some objectivity to the evaluation of who should be a subject protected by the assistance policy, adding other judgment variables to the body that are not only the biomedical discourse on lesions, diseases or disabilities. Some disabilities don't generate controversies in a medical evaluation, such as mental disabilities or serious cases of functional restriction like quadriplegia or severe bilateral deafness (DINIZ et al., 2007a). However, most cases analyzed by inspectors do not fit in these clear limits of the biomedical discourse that considers disability the absence of specific functionalities and this makes it

difficult to measure the "incapacity for independent life and work" (BRASIL, 1993, 2007b).

There is a centrality in the values of independence and market insertion for the judgment of eligibility for the benefit. Both are summarized in Decree 6.214, of 2007, by the concept of incapacity as "a multidimensional phenomenon which contains limitation of activity performance and restriction of participation with effective and pronounced reduction of social inclusion" (BRASIL, 2007b). So as to receive the benefit, reduced social inclusion is understood as the lack of school participation for the kids and job market for the adults. As a result, the clinical condition to be judged by medical inspection should have as an evaluation standard to what extent the disease, disability or lesion restricts the individual's social participation. However, the variables to measure participation are, essentially, independence and work.

By independence, one understands the ability to perform everyday life activities, such as personal care, nutrition, hygiene and locomotion; conditions specified in the previous document used by physicians during inspection. Since for children these are routine conditions to experience childhood care, the school becomes an essential datum to evaluate social inclusion. In recent years, a change in the disability evaluation format ceased using AVALIEMOS as a guiding tool (BRASIL, 2007a), even though the medical inspectors still conduct evaluations following the items of the past tool.

The clinical and labor history of the disabled person is taken to the first session of the medical inspection. In the case of adults, the history of market insertion is one of the first criteria of assessment of the body that goes beyond what can be seen in the inspection. The work history offers information that allow us to bound the dependency and incapacity account announced by the disabled seeking benefit. Work is a central variable for inspectors because it indicates the body's capacity to have independence, social insertion and productivity. The fact that one has already worked does not make the disabled person ineligible to receive the benefit, even if it is privileged information to measure the degree of the exclusion experience reported by the individual.

For adults, the tools used in medical inspection are medical reports and the work history available in the Social Security Pension Fund; for children, they are medical reports and information on school attendance. The social report, whose objective is especially attesting family and individual poverty, is already available to the doctor before the disabled individual reaches the INSS center. There is little room, in the structure of the inspections, to reelaborate on poverty considering something different from the 1/4 of minimum wage, taking into account factors such as expenses with medication and medical treatments or specific expenditures required to assist the disabled person (MEDEIROS et al., 2006).

In this scenery, for disabled adults, assessing the body contrasting it to labor incapability becomes the central axis of medical inspection, because the existence of an objective variable is assumed to measure social

exclusions. The result, however, according to one of the participants of the research, is that the inspection becomes so restrictive in its criteria that it tends to favor only “*people in a near vegetative state*”.

Work and social inclusion

The metaphor of a vegetative state is a challenge to the restrictive character of medical inspection in defining the bodies that will have access to the benefit. If for limit cases, the ICD attached to the medical report is enough to insert the individual in the social protection system, for all other cases, which are the majority, it is the interpretative negotiation of how that body interacts socially that defines the eligibility to the BPC. Table 1 describes health conditions that made an individual eligible to the benefit after medical and social reports:

Table 1 - Benefits granted

| Medical reasons | People |
|--|--------|
| Physical and motor disabilities | 9 |
| Mental disabilities | 8 |
| Chronic diseases in advanced stage | 9 |
| Sequelae of a cerebrovascular accident (CVA) | 2 |
| Genetic diseases | 2 |
| Total | 30 |

Source: “Disability at issue” Research, conducted during the years 2006 and 2007 in Unaí-MG

Along with a great number of physical and mental disabilities, cancer, aids and diabetes also showed up, all in advanced states. The identification of these diseases indicates an extension of the disability concept used to grant BPC, in an interpretative movement that goes beyond the biomedical catalogue which limits a border between diseases and disabilities (MEDEIROS et al., 2006; DINIZ et al., 2007a; SQUINCA, 2007). Table 2 describes cases in which the benefit was denied for medical reasons, even though the individual was in the income category required to have access to the benefit:

Table 2 - Reasons for denial

| Medical reasons | People |
|---------------------------------|--------|
| Physical and motor disabilities | 4 |
| Chagas disease | 4 |
| Vascular diseases | 3 |
| Arthrosis | 3 |
| Chronic diseases | 1 |
| Leishmaniasis | 1 |
| Ulcer | 1 |
| Epilepsy | 1 |
| Hydrocephalus | 1 |
| Total | 19 |

Source: “Disability at issue” Research, conducted during the years 2006 and 2007 in Unaí-MG

The medical profile of the second table shows that people who have acquired diseases have fewer chances to be considered eligible for BPC, even if these diseases are considered incapacitating and affect adults. This is suggestive data that shows how medical inspection defines body outlines for the BPC - permanent health conditions with no resources for treatment or cure, or congenital problems are more easily understood as diseases when compared to those acquired and directly resulting from the interaction of the body with social life, such as the so called poverty diseases (ISHITANI et al., 2006) like leishmaniasis, Chagas disease and vascular diseases. Even though these may be conformations acquired by the body and not exactly disabilities in the biomedical sense, when associated to poverty, to the lack of access to health services and to a non inclusive labor market, they challenge the fine line between disease and disability. This reformation casts a question about what would be the difference between an individual with serious and incapacitating sequelae of the Chagas disease and an individual with a serious mental disability, if both are in a situation of social exclusion and poverty due to the body they inhabit.

There are cases in which the seriousness of the lesions define a kind of disability with little room for medical dispute as to the eligibility for the benefit: for example, children and adults with mental disabilities and chronic diseases in near terminal stages. Between the extreme that groups the objective cases of disability for biomedicine and the diseases acquired throughout life - such as Chagas, arthrosis, vascular diseases or ulcer - there is a limit that makes biomedical view on disability the safest grounds so that the inspection classifies the outlines of the body for the BPC. The disabled body must be one defined by irreversible incapacity for productive work and severity of functional restrictions. But the interesting this is that incapacity for work is not restricted to the limitation of body abilities, such as productive performance, cognitive capacities or physical strength.

The definition of which body is able to work is not the result of a strictly biomedical narrative on normality and its variations in the human species. No medical catalogue of functions and dysfunctions in the species is able to foresee the diversity of expressions the body acquires and its postulation for social protection by the BPC. The incapacity to work is translated by a medical report that exhibits an ICD, but it is a text about a body that, beyond biomedicine, considers social expectations on the efficiency of bodies for productive work. The report of a disabled body eligible for BPC is not a descriptive and objective act on lesions, but a moral discourse over which social expectations are not susceptible to be fulfilled by certain bodies. It is this incapacity to adequate to the work norm, defined by contrast to an ideal of a productive subject, that is expressed in the medical inspection when an individual is included in social protection.

There is a relation of continuity between lesions, stigmas and social exclusion. A body with lesions is the

object of ethical and esthetical rejection, which results in the social exclusion of disabled individuals, confined to domestic life. There is a permanent stigma that generates rejection to the disabled body, proclaiming its inadequacy to the productive work rules (GOFFMAN, 1988). The requirement that the disabled people also be poor to have access to BPC clouds the borders on the origins of social exclusion - if it's the oppression of the body with lesions that leads to poverty or if it is poverty and expressions of inequality that come with it that makes the disabled individual vulnerable. For the disabled people with chronic diseases not considered incapacitating for medical inspection, such as poliomyelitis sequelae or rheumatoid arthritis, the marketplace exclusion narrative should be a should be a variable added to biomedicine to attest the incapacity of the individual for independence.

Two factors keep a person from having access to BPC. The first is income, that is, people with a family income above 1/4 of a minimum wage *per capita*, even if poor, cannot receive the benefit. The second is the lack of a proof of incapacity for independent life and work, according to the medical inspection assessment. In these cases, the medical discourse recreates the social exclusion narrative presented by the subject - poverty and inequality do not derive from the body, but from other factors. Having the benefit denied by a medical inspection that considers the body able to work can happen for two reasons. First, a fraud attempt, that is, the person does not have a lesion, disease or disability that indicates eligibility to the benefit, but tries to earn an income through the BPC. This is a reasonably easy situation to be identified by medical inspectors. But the challenge lies in the second reason, that is, when the outlines of the body to attest one's incapacity to work are not so clear as the biomedical narrative on normality and its variations would suppose.

Assuming the ethically defying cases are those in which there is no fraud and the individual is actually poor, the question after a benefit is denied is how to make a body that presents itself as non-productive become a body that biomedicine asserts to be productive. Medical report, not recognizing the incapacity to work, also advertises the potential productivity of the subject and removes him/her from the social protection range based on disability. Among the medical diagnosis refusing access to benefits were cases of chronic renal disease or Chagas' disease, whose impact on the body demands different adjustments in the work order to recognize the productive power in the individuals. Of the 28 people with disabilities that requested the benefit and had it denied after medical inspection, only 4 worked and 24 declared not working in the previous year due to lesions, diseases or disabilities in the body. Different from the medical inspection that rejected the dependency thesis, the individuals describe themselves as having an incapable body for productive work.

This results in a dispute on whether the body is entitled to receive the benefit. Recognizing the complexity of assessing body outlines doesn't mean ignoring the

importance of biomedical narrative to classify potentially productive and independent bodies or disabled ones. If there is something that may be objective in this discursive scenery about bodies, it is still the poverty confirmation and medical classification. However, what the refused cases demonstrate is that these two inspections are still insufficient to guarantee a fair granting of social protection to disabled people.

Medicalization and dependency: appearance of the disabled child in an adult body

Putting together incapacity to work and medicalization of the disability for the granting of BPC is also in the difference between assessing the children and adults with disability. In the case of children and teenagers under 16, how much labor capacity is affected by disability is not assessed, on the other hand the impact disability has in performing everyday activities and restricting social participation compatible with the age is (BRASIL, 2007b). Restrictions in social participation in the case of children is equivalent to the incapacity to work in the case of adults, even though their social participation is essentially understood as attending school.

Children and teenagers up to 16 years old with disabilities are the greatest share protected by the BPC: one in every 4.5 benefited people is in this age group (BRASIL, 2007a, 2009). Having restricted functionalities and depending on constant care, added to childhood itself, immediately favors the ascension of disabled children to eligibility for the assistance benefit. In turn, adult disabled bodies have to simulate the children's situation to receive the BPC: the seriousness of the restriction of body abilities and the dependence to perform everyday actions such as feeding, taking care of oneself are decisive to grant the benefit. The body characteristics are assessed having the conjunction of severity of functionality restrictions and irreversible work incapacity as a parameter.

The parallel between the evaluation of the bodies of children and adults to access BPC illustrates the strength of arguments about independent life, availability of the body for productivity and access to social opportunities offered by work. All these values structure different ways of translating which lifestyles are admitted, but it is necessary to question the relevance of planning public repairing policies that will guarantee minimum survival amounts, such as the BPC, having these amounts as purposes of the social protection policy. Instead of the labor capacity being the central variable to judge who can have access to social protection, why not think it in terms of how to promote and guarantee principles such as equality and dignity.

Determining the aspects of the body that make a person eligible for the assistance benefit is not a simple task, but, for the operationalization of policy, it is a decision that must be taken some day. Finally, defining how the inspection tools should be may draw limits between who should and who shouldn't be protected by a repairing public policy. If disability is frequently related to

limitations in the performance of basic life activities with some dignity (DINIZ et al., 2007), the repairing public policies attempt to remove inequalities and injustices related to the performance of these activities. Thus, the BPC attempts to determine which body expressions are considered as involuntarily disadvantageous and, this, in need of protection against inequalities in a relation of body and society. In order to accomplish this, inspection tools should identify the greatest number of social components of the experience and disability, since the biomedical perspective tends to restrict the disabled body to pathology and dysfunction notions (DINIZ, 2007; DINIZ et al., 2007a; SANTOS, 2007).

The benefit regulation model and how medical inspection is structured are two factors that favor planning BPC for bodies with severe functionality restrictions. Even the disease cases (Aids, cancer, diabetes) incorporated to the disability concept for the BPC in the past years only reached levels of incapacity when in advanced state, that is, involving a disabled body in an irreversible incapacity to work and under intense medication. For the inspectors, the election of bodies in a “vegetative state” happens because the laws don’t give room to other interpretations and only medical inspection is insufficient. Some inspectors report that “*there should be more than one inspection, other professionals besides doctors and even home visits to check on the socio-economical of the individuals requesting BPC*”. Meanwhile, the inspections follow guidelines indicated by the assistance legislation, which results in the fact that only severe disabilities are protected by the BPC.

Final considerations

In Brazil, education and labor market are two areas in which disability has started being considered priority to promote inequality. The sensitivity of these two areas results in a change of perspective about the disability that has been guiding the actions of several countries as of 1970. Before this, the resources to deal with disabilities were limited to the advances offered by biomedicine and rehabilitation techniques. The biomedical resources were important to improve the health standards of disabled people, but treating disability as a topic in the scope of equality requires policies in other areas besides education, labor market or health.

Medical inspection is a central issue in assessing the outlines of disabled bodies for social protection. However, the concept of disability is not restricted to a catalog of lesions, disabilities or diseases to determine which body is incapable of having an independent life and working, two variables that guarantee eligibility for the benefit. There are nuances, severities and subtleties in health and disease conditions, which demonstrate the insufficiency of biomedical narrative to classify bodies. Disability is not only a medical concept or an embodiment of a dysfunctionality classification: it is especially an expression of a complex relation between body and society, in which stigmas, exclusion and oppression operate.

The adoption by the BPC of the understanding of disability established on the ICF should be considered progress to affirm that social protection is an instrument of equality promotion. As of 2009, the disability bodies will be evaluated according to the ICF, a complex catalog that proposes a new language for disability besides biomedicine (DINIZ et al., 2007b). However, the incorporation of a new concept of disability by the BPC will be a challenge for the implementation of public policy and for the consolidation of social rights to disabled people. A great challenge will be making new medical criteria explicit for the judgment of the outlines of disabled body to have access to BPC.

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Notes

1. People with disabilities, disabled people and disabled will be used as synonyms in this article.
2. In the definition of the criteria to access the BPC in LOAS, 1993, a person’s disability had to incapacitate the individual to work and also to an independent life. The requirement of an incapacity for independent life was considered by many specialists a variable difficult to measure in the inspection process to give access to BPC. In 2008, this incapacity was no longer an assessment criteria after the Normative Instruction of the INSS, as a result of a Public Suit of the state of Acre filed by the Federal Prosecuting Counsel, which determined that the INSS assesses, in order to grant BPC to disabled people, only the incapacity to work and poverty.

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Debora Diniz is an anthropologist and tenure professor at the University of Brasilia. Nowadays she is a senior researcher at Anis: Institute of Bioethics, Human Rights and Gender, an independent group which she co-founded, and researcher at the National Council of Research (CNPq). She has 63 peer review papers, 47 book chapters, 7 books, 9 edited books, 98 newspaper articles, 5 films and 43 awards. She develops research about bioethics, research ethics, reproductive rights, secular state and disability, sponsored by CNPq, Ford Foundation, Prosare, Finep and Ministry of Health. She is co-editor of *Developing World Bioethics* journal and co-editor of original paper of RECIIS, and also a member of the editorial board of 9 peer review journals. She is the head of the research ethics on social science committee at the University of Brasilia. Her most recent edited book, "By the cinema lens: bioethics and research ethics", in partnership with Dirce Guilhem and Fabio Zicker, was nominated for the Jabuti Award as the one of the top ten best books in 2008.