Editorial

Disability and accessibility: a national discussion is imperative

Studying, researching, discussing, speaking and writing about one of the most important topics, which is part of our social and human concerns, is a challenge that must be faced in the proper context: bioethics. Issues of disability and accessibility refer to the fundamental rights of the individual, the Brazilian Constitution, the legislation in force in the country, the Sistema Único de Saúde - SUS (Brazilian Unified Health System), as well as ethical concepts and theories, and principles of justice such as autonomy, equity, social exclusion, morality, utilitarianism, and vulnerability, among other issues discussed by contemporary and non-contemporary bioethicists and philosophers.

Article 5, subsection II, of the Brazilian Constitution guarantees *that no one shall be obliged to do or not to do anything other than by virtue of law*[1]. Subsection XIII states that *the exercise of any work, trade or profession is free, subject to the professional qualifications that the law prescribes*[1]. At least eight other articles are specifically aimed at citizens with disabilities, covering discrimination, protection and social integration, quotas for public posts and jobs, qualifications and rehabilitation, specialized educational services, creation of preventive programs, as well as standards of construction and adaptation of public places, buildings and transport existing at the time of the promulgation of the Constitution. Most of these determinations have not been complied with.

Lei 13.146/2015 [Law 13,146/2015][2] – the Brazilian Law on the Inclusion of Persons with Disabilities - repeats the concerns of the Constitution and adds other guidelines. Article 2 defines a person with a disability as *one who has a long-term physical, mental, intellectual or sensorial disability, which, in conjunction with one or more barriers, may obstruct their full and effective participation in society*[2]. Article 4 establishes that *every person with a disability has the right to equal opportunities with others, and will not suffer any kind of discrimination*[2]. It also considers, in paragraph 1, that discrimination is *any form of distinction, restriction or exclusion by action or omission, that has the purpose or effect of impairing, preventing or nullifying the recognition or exercise of the fundamental rights and freedoms of persons with disabilities*[2].

According to article 9, *the disabled person has the right to receive priority service* (...) *in all institutions and public services.* In addition, *the qualification and rehabilitation process aims to develop the potential, talents, skills and abilities* (...) *that contribute to the achievement of the disabled person's autonomy and their social participation within equal conditions and opportunities with other people*, as specified in Article 14[2].

The latest demographic census by the Brazilian Institute of Geography and Statistics[3], conducted in 2010, shows that there are 45.6 million Brazilians with at least one type of disability, of whom 32 million are in the age group between 15 and 64 years of age, 6.7% have completed higher education, and 61% have no education or have not completed basic education. Visual, motor and auditory deficiencies predominate in this group, respectively. Of the non-disabled population, 10.4% have completed higher education and 38% have no education or have not

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completed basic education. There is, for example, a predominance of black women with disabilities. However, there is a higher level of employment among men with disabilities, repeating the inequality between men and women without disabilities in employment, roles and salary opportunities, which could be considered inequality of gender and colour, heightened by disability.

According to the Annual Social Information Report[4] for 2014, the number of places occupied by someone with a disability corresponds to 381,300 or 0.77% of the total jobs in the country. Men occupied 64.45% of the job vacancies, while women had a total of 35.55%. In analysing the topic "Clinical bioethics, biopolitics and social exclusion," Anjos states:

> *(...) dealing with social exclusion is like dealing with bad news regarding health. This is an unpleasant subject even when addressed only in theory. This is due in part to the fact that it is always painful to get in touch with the needs, pain and suffering of people, and also because such situations disturb the peace as they become a question mark underlying our personal attitudes to facts. In this way, an almost a priori rejection reaction to the topic is not rare*[5]*.*

So why would it be any different in dealing with the issue of disabled persons? The Sistema Único de Saúde - SUS (Brazilian Unified Health System), which was instituted with the Constitution[1] in articles 196 to 200, faces serious problems, created largely by mismanagement, low funding, incompetence, corruption and disregard for equity apropos access and social inclusion. In short, a lack of commitment regarding the health of the population.

After 30 years since its creation, SUS needs to be rediscussed. One should not fear improving the achievements of citizenship - it is necessary to resume the debate on modernization of management and forms of financing, as well as social and governmental control, without losing sight of equity and justice, aiming at the health and well-being of the population, and not lesser interests.

Perhaps even proponents of Bentham's utilitarianism[6] would agree, as improving SUS would be to avoid pain and suffering, and to determine pleasure and happiness. The point is that the 25% of the population that do not depend exclusively on SUS apparently have more power than most. Therefore, it is worth asking: how can diverse interests be delimited? How to know that the moral commitment of the government will not put it on one side or the other? How to ensure that justice and equity are prioritized?

We know, for example, that when there is religious or moral disagreement among the population, the government, or one of the three powers, should not choose one side but remain neutral and try to mediate the conflict. However, this is not what happens routinely in Brazil. Sometimes, in addition to choosing one side, rulers punish those who think differently, usually the most disadvantaged.

Regarding this dilemma, Sandel comments that the fear of punishment is legitimate and asks the question: even if it is not possible for the government to remain neutral, would it be possible to conduct politics on the basis of mutual respect? The answer, he believes, is yes, but related to the fact that *we need a healthier and more engaged life than the one we are used to.* A more robust public engagement with our moral disagreements could provide a stronger, not weaker, basis for mutual respect. *A policy of moral engagement is not only an ideal more inspiring than a policy of avoidance of debate, but also a more promising basis for a just society*[7].

However, what we currently have in Brazil is a chaotic health system, often inhumane, that does not fulfil the moral and constitutional commitment, which refers to the impertinent inequalities and disrespect for the fundamental rights of the individual to equity. How does one evaluate what happens when a person with disabilities needs care in a unit from SUS?

Nunes[8], when analysing the social regulation of health and the rights of patients in Portugal, cites article 25 of Decreto-Lei 309/2003 [Decree-Law 309/2003][9], which established the Health Regulatory Entity and provides, among other objectives, *the ensured right to universal and equitable access for all to the public health service*[10]. The author[8] mentions 12 patient's rights, all evidently relevant and fundamental, contained in the proposed charter of patients' rights and duties[11]. Of these we cite five: 1) autonomy, 2) privacy, 3) non-discrimination and non-stigmatization, 4) equity in access, and 5) accessibility in a timely manner[8].

It is not intended to compare the systems of the two countries, but SUS is currently likely to face many more difficulties. We can easily imagine the effort of citizens to have access; waiting for care, without comfort or safety; the lack of minimum reception conditions, which includes: dignity, trained and qualified staff, available examinations and medicines. We can also assume what happens when people with disabilities became ill and seek the public health system in Brazil. Their difficulties will be greater, even though Lei 13.146/2015 [Law 13,146/2015][2] guarantees them priority care.

In discussing *autonomy and vulnerability*, Monteiro[12] concludes that the clear relationship of interdependence between these categories does not only point to the limits of the application of autonomy as a moral principle inherent in respect, in the impossibility of an action that is perfectly autonomous, but only substantially. He cites the difficulties in determining criteria that define actions that are substantially autonomous, aggravated by the poor social and educational conditions of part of the Brazilian population.

The author refers to Neves[13] and his important consideration regarding the inseparable relationship between vulnerability and autonomy: *The notion of vulnerability as a moral principle linked to the principles of autonomy, dignity and integrity arises from the* Barcelona Declaration. *This states that the finitude and fragility of life are concretely explained in people capable of autonomy*[13]. Neves also states that, *in addition to confirming the already stated impossibility* [of] *autonomy to suppress vulnerability,* (...) *it is this dimension of the humane, which is the susceptibility of being "harmed", which establishes the duty of not "to harm"*[13].

How can we guarantee equity in a system that excludes the weak, the less able, the ones who had less opportunity, therefore determining inequalities and perpetuating them? In addition to the difficulties of day-to-day accessibility, the person with disabilities faces iniquitous treatment at health facilities. Of 24 units visited by the inspectors from the Regional Council of Medicine of the State of Rio de Janeiro and by medical students[14], none had adequate conditions for accessibility. In addition, 54% were inadequate in all six adaptability items evaluated, 29% had only one item that had been adapted and 17% had two items.

From this pilot project[14], the Conselho Federal de Medicina - CFM (Brazilian Federal Medical Council) established a protocol in the National Surveillance System, which covers all Conselhos Regionais de Medicina - CRM (Regional councils), in order to make possible a national diagnosis. Another concern is to know the disabled health professionals. How many are they, what are their predominant types of disability, where do they come from, if the unit in which they practice their profession has been adapted, among other key information. Since two years ago, the CFM has been offering space for the insertion of this data at the time of registration, or re-registration, in the CRM.

We put forward a suggestion for a national discussion, which can be addressed in all areas of health: that initiatives be made to expand working groups, commissions or technical chambers of bioethics, so that these professionals who take care of the population’s health can be known. It is fundamental to listen to their difficulties, to know their needs, to help those who need assistance, supporting them in the exercise of their jobs and contributing to their integration into the work environment. This recognition and encouragement will benefit the population served by these units, the raison d’être of these professions and of this science, extending the benefit to students who attend such theoretical-practical learning environments. We will thus be fulfilling our role as citizens and guardians of the population’s ethics and health.

We believe, like Professor José Eduardo de Siqueira, that bioethics can be used as a political instrument of transformation and that the best way of answering questions related to its universe, as the ones discussed in these lines, come from deliberate reflection aiming to achieve conscious decision-making.

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