Chapter 14

Bioethics And Public Health Care For People With Disabilities

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ABSTRACT

This paper discusses bioethics and public health care of people with physical disabilities. Proposing to think about the importance of Bioethics insert themselves in the context of disability and include it in its context, taking the family as a reference. The subject is increasingly relevant, as are many obvious changes, challenges, and achievements for these people in recent years. It is a literature search, which used books, journal articles, and websites specialized area. In this paper, we find growth concerning acquiring autonomy and conquering their spaces. Much has been discussed about health and the matter is still far from being exhausted because the concept of health has become increasingly widespread over time and becoming synonymous with the necessities of life. In this context, it is clear the importance and urgency of producing research in the area of Public Health so that appropriate action can be mobilized and be closer to reality and appropriate social and basic needs of life of the disabled, therefore the lack of information and knowledge of the people on issues concerning the disabled brings a big problem for the Brazilian population, in most cases, only after being attacked a case of deficiency in the family that is seeking to demolish prejudice and mobilize forces for the recognition and legitimization of the rights of PPD, which in the short and immediate term is impossible to achieve if the goal is to achieve concrete and sustainable results.

Keywords: *Bioethics, Public Health Service, Physically Handicapped.*

1 INTRODUCTION

Some time ago talking about disability was more difficult, as it was a subject permeated by taboos and prejudices. Hiding made it better. Today, in the face of public policies that are increasingly open to this population, guaranteeing them basic rights and giving them spaces where they assume their citizenship, being disabled is no longer what it was years ago.

GAIO (2006) addresses the issue of disability only as a "limitation that for some reason they acquired not only by biological inheritance but by unresolved basic social problems, such as access to education, health, housing, among others". (GAIO, 2006. p.26)

Diniz (2006) points out that disability idealizes the variation of characteristics, which may be in the body or some ability, taking into account the injury or restriction. There are still challenges to arriving at a determining factor to define the disabled population.

This article aims to address the issue related to public health care for people with disabilities and bioethics. The methodology used in this article was bibliographical research, which used books, scientific articles on the proposed theme, and specialized sites in the area.

All people, including those with some type of disability, have the right to access education, health, leisure, and work. These areas contribute to social inclusion, the development of a healthy life, and an inclusive society (PABLUICA, 2007, p1).

Persons with disabilities have the right to exercise these rights and to strengthen their participation as citizens.

2 BIOETHICS: CONCEPT

It is important to point out that Bioethics does not have a single concept, and can be understood by different currents, trends, and Schools, which, according to geographical and cultural criteria, adopt such an understanding to their context.

According to Garrafa (2005, p.35), “the understanding and practical application of what bioethics is at the beginning of the 21st century varies from one context to another, from one nation to another and even among different scholars from the same country. ”.

As for the word Bioethics, such a neologism was coined by the oncologist Van Ressenlaer Potter, in 1971, with the aim of, by joining in a single field the knowledge of biology and ethics, helping humanity towards rational but cautious participation in the process of biological and cultural evolution. (FONTINELI JR, 2002, p.14).

The literature has referred to Bioethics as the ethics of life. Its word comes from the Greek root bios and ethos, meaning life and ethics, respectively. According to the Encyclopedia of Bioethics, “bioethics is the systematic study of human conduct within the scope of life and health sciences, while this conduct is examined in the light of moral values and principles”.

On the other hand, Bioethics can be used as a “coordination mechanism and instrument of reflection to guide knowledge, due to an increasingly responsible protection of human life”. (ROY, 1999, p.23).

2.1 HISTORIC

Bioethics arises from man's need to seek a look at the world that allows “a secular, interdisciplinary, prospective, global and systematic approach to ethical issues and the affirmations and constructions of human rights that mark the world”. (DURANT, 1995, p.18).

Initially, Bioethics was almost strictly related to Medicine and the consequence of its research with human beings or the scientific and technological advances in this area, thus arising questions and limitations in the practice of these professionals.

Professor Goldim explains that “norms were already present in the first code of humanity that regularized the practice of health professionals and led to care for life.” Briefly, this tells us about the emergence of philosophical guidelines about Bioethics.

The main event remembered by most scholars that marked the beginning of thinking about Bioethics is the Nuremberg Code.

According to Reich (1995, p.18), the pioneers of Bioethics were Van Rensselaer Potter and André Hellegers, when they made their contributions public, as Potter:

> At the University of Wisconsin, who first coined the term bioethics (bioethics) when writing the book Bioethics: 'bridge to the future', in 1971, and André Hellegers, from Georgetown University, who first used it in an institutional context to designate the research area or field of learning.

Potter in his literature aimed with Bioethics, “to join in a single field the knowledge of biology and ethics, to help humanity towards a rational but cautious participation in the process of biological and cultural evolution through discussions and reflections”. (ZOBOLI, 2000, p.03).

In Brazil, ANIS points out that Bioethics has been developing within the domains of University institutions, through centers and research institutes located in all states, showing its importance and contributions in the areas of health, law, and other areas.

Finally, Callahan (2002, p.19) points out that "Bioethics is a new field, seeking a better definition of itself, as well as a redefinition of its methods". It already has a beginning in defining its direction and possible contribution, but it is still a beginner in the face of so many questions that intertwine and absorb the complexity of life, ignorance about the future, and uncertainty of survival.

3 HEALTH

Many health concepts were created in the quest to improve society's quality of life and in 1980 the World Health Organization defined health as:

> Both as the absence of disease, as complete physical, psychological, and social well-being, or ability to overcome physical, psychological, social, cultural, and symbolic difficulties, or even as a normal pattern of behavior, which would be opposed to that defined as pathological.

This concept was an important step towards the evolution and conquests of humanity until today reaching the concept of health as the basic life needs of every citizen, such as access to education, work, housing, a healthy lifestyle, leisure, basic sanitation, food, health services, etc.

And this conception is precisely what the National Health Policy defends, which calls health:

> A characteristic incorporated into each individual, participating in his existence and the definition of his person, resulting from the interaction of individual factors, including genetic ones, with environmental factors. Understood in this way, health cannot be detached from the individual, constituting an aspect for which someone else may have control or primary responsibility, except in the specific cases of minors and incapable persons (emphasis added). It is, therefore, a field of joint responsibility of the individual, the family, the company, other community institutions, and the State. The definition of specific areas of responsibility has no parameter other than the

> characterization of the degree of control that each of these levels has over the causal factors of the health problem.

It should be noted that there are still two other meanings defended by this Policy, in which, “health refers to the field of study related to the biopsychosocial balance of man with his environment. As such, it is the object of study and interest of the health sciences” (BRASIL, 1997, p. 161).

And the third and final meaning is that "health refers to the productive sector formed by the set of legitimate service providers whose explicit purpose is to promote, preserve and restore human health" (BRASIL, 1997, p. 162).

On the other hand, if the fight for bidding and conquest of constitutional rights lasted for many years until the social groups were able to mobilize, the biggest existing struggle is the legitimization of these conquests, otherwise, it hinders the realization of these rights and, therefore, the improvement of the quality of life of the population, which, in general, is already lagging.

People with disabilities, with all the problems of accessibility, health care, education, housing, leisure, and often dependence on other people to help fulfill their basic needs in life, as history demonstrates, have been overcoming obstacles of prejudice through the mobilization and organization of social forces, mainly with the support of their families, in the search for the implantation and implementation of the rights reserved for people with disabilities.

According to BRASIL (1997, p. 161): “The definition of the health/disease phenomenon comes up against the difficulty of obtaining, at the same time, a formulation that covers the entire breadth and complexity of the phenomenon and lends itself to operational purposes”.

Therefore, there is nothing more coherent than for people with disabilities and their own families, together with public bodies, to adapt public policies to the basic needs of people with disabilities.

3.1 HEALTH CARE FOR PEOPLE WITH DISABILITIES

The disabled population succumbs to the lack of public health policies, but this deficit is not restricted to people with disabilities, as “equals” also suffer from the precariousness of these policies, such as the scarcity of public institutions in the area of hospital health.

There are several precursor causes of deficiencies, and Public Health is of fundamental importance in the control and prevention so that the rates can be reduced.

> Law No. 7.853/89 itself, which provides for the rights of Persons with Disabilities, in its Article 2, deals with the responsibilities of the Public Power, defines its areas of action as prevention, including the prevention of accidents at work and Traffic; the creation of a network of rehabilitation services; guaranteed access to public and private health facilities; home health care for severely disabled people who are not hospitalized; and the principle of society's participation in the sector's programs. The law assigns, not only to this segment but to society as a whole, special attention focused on prevention, such as actions to reduce the rates of injuries that lead to disability (BRASIL, 1998, p.62).

Secondary deficiencies, that is, their aggravation, are caused by the precariousness of public health policies, in which they are responsible for promoting health services, education, housing, employment, transportation, leisure, and basic living conditions, which are legitimate components of citizenship.

In addition, the insistent centralization of the health system increasingly implies the difficulty in meeting the exorbitant demand for these conditions and in articulating the public health policies that are attributed to the three instances of the Government (Federal, State, and Municipal), in which incorporate crucial participation and responsibility for the control and improvement of the health and quality of life of the population, because, according to the principles of the SUS, art. 282:

> The National Health Council and the Ministry of Health must ask the Ministry of Education, the Councils of Health professionals and universities, and other higher education institutions, public and private, about curriculum review processes, to humanize the relationship between the health team and SUS users, ensuring: the training of trained professionals to provide comprehensive care to people with disabilities and chronic pathologies, through the creation of multidisciplinary care, teaching and research centers within public universities and private (BRASIL, 1998, p. 69).

In addition, the promotion of these policies includes the fight against diseases associated with these limitations, such as sedentary lifestyle and depression, classified as secondary due to the social isolation of people with disabilities arising from prejudice and the low quality of life of the population, not providing a happy and productive life for People with Disabilities, who have a lifetime proportional to the basic living conditions to which they are submitted.

3.2 PUBLIC HEALTH POLICIES FOR PEOPLE WITH DISABILITIES

Due to the limitations imposed by intellectual, physical, auditory, or visual impairment, people with disabilities end up adopting a sedentary, dependent life outside the social context, and, in this regard, health promotion through the practice of physical activity can bring great benefits to the individual with some limitation, because, in addition to preventing diseases and recovering health, it works on participation, cooperation, decision-making and autonomy, and not dependence linked to the curative and assistance perspective.

This policy has the purpose of "rehabilitating people with disabilities in their functional capacity and human performance – to contribute to their full inclusion in all spheres of social life – and to protect the health of this population segment, as well as to prevent injuries that determine the appearance of disabilities" This policy establishes the following guidelines:

> Promotion of the quality of life for people with disabilities, comprehensive health care for people with disabilities; disability prevention; expansion and strengthening of mechanisms for information, organization, and operation of care services for people with disabilities; and training of human resources" (Brasil, 2006, p.25)

The training of human resources emphasizes the need to qualify professionals, and the intersectionality to guarantee the right to health care established in this policy. It is noteworthy that the

National Health Policy for Persons with Disabilities adopts the same concept established by Decree 3,298/99 in its art. 4, Items I, II, III, IV, and V.

Health services must work by serving the individual as a whole human being. The health care model for the elderly must, therefore, be necessarily and obligatorily based on the principles and guidelines advocated by the SUS. This implies understanding the care model referenced in health promotion, disease prevention, rehabilitation, and health care.

3.3 ACCESSIBILITY

Accessibility is the ease of access for people with disabilities or reduced mobility in the social environment, without any type of barrier (SASSAKI, R. K, 2003).

Accessibility to built space should not be understood as a set of measures that should favor only people with disabilities, as it could even increase the spatial exclusion and segregation of this group, but technical and social measures aimed at welcoming all potential users (DUARTE; COHEN, 2004).

Accessibility emerges as an obligation for people with disabilities so that they have the same possibilities to enjoy any services such as leisure, tourism, and work. The various laws and public policies already guarantee accessibility, although not all measures are complied with due to the lack of inspection and goodwill of companies and service providers.

Accessibility, according to Law No. 5.296/2004 (BRASIL, 2006, p.57) is:

> The condition for using, with safety and autonomy, total or assisted, spaces, furniture and urban equipment, buildings, transport services and devices, systems, and means of communication and information, by a person with a disability or with reduced mobility.

An accessible environment can be used and experienced by anyone, including those with some type of disability. An adapted environment is modified after its initial construction, to become accessible, although an adaptation will not always guarantee people's independence.

All the achievements achieved in the field of accessibility were possible due to the awareness and struggle of a part of the population for the inclusion of people with disabilities in society. It is the model of inclusion that is advancing towards an egalitarian society, with the same leisure and tourism rights for all.

4 CONCLUSION

Ethics aims at understanding the criteria and values that guide the judgment of human action in its multiple activities. Based on values, it seeks the fundamentals that guide behavior, aiming to guarantee social cohesion and harmonize individual and collective interests. Thus, ethics becomes increasingly necessary in the exercise of any profession.

Ethical values were understood in this work as principles that guide our actions. Therefore, we analyze the values that guide health care for people with disabilities. Care depends on an ethical conception that considers life as a valuable asset in itself.

In the exercise of the profession, the nursing profession must respect life, dignity, and human rights in all its dimensions, respect is a fundamental value in professional practice. Today, the great challenge for health professionals is to take care of human beings in their entirety.

This a challenge, as there are many obstacles to achieving comprehensive care. Difficulties were mentioned to guarantee the respect and dignity of the patient concerning the precarious physical structure and insufficient material and human resources.

Health professionals must exercise their profession responsibly, as well as protect the person under their care from damage caused by malpractice, negligence, and recklessness. Negligence consists of the lack of attention; malpractice, in the absence of knowledge, ability, or dexterity; and imprudence, in the hasty attitude, taken without reflection about the consequences.

Above all, it is necessary to make an effort to treat hospitalized elderly patients, recognizing their specificities, encouraging their independence, guaranteeing their access to the therapeutic resources available and indicated for their case, as well as respecting their autonomy.

REFERENCES

BRASIL. **Participando das Políticas e Ações: Série Política Municipal Para a Pessoa Portadora de Deficiência.** Brasília: CORDE, 1997, p.161-162.

O Município Para Todos: Série Política Municipal Para A Pessoa Portadora De Deficiência, 1. Brasília: CORDE, 1998, p.62-69.

Direitos e Garantias: Série Política Municipal para a Pessoa Portadora de Deficiência. Brasília: CORDE, 2006, p.25.

Decreto-lei nº. 5.296, de dezembro de 2004. Regulamenta as Leis nº 10.048, de 8 de novembro de 2000, que dá prioridade de atendimento às pessoas que especifica, e nº 10.098, de 19 de dezembro de 2000, que estabelece normas gerais e critérios básicos para a promoção da acessibilidade das pessoas portadoras de deficiência ou com mobilidade reduzida, e dá outras providências. Brasília, 2004. Disponível em: http://www010.dataprev.gov.br/sislex/paginas/23/2004/5296.htm. . Acesso em: 24 abr. 2006.

CALLAHAN, Daniel. **Judging the Future: Whose Fault Will It Be?**, The Journal of Medicine and Philosophy, 2002, p.19.

DUARTE, Cristiane Rose; COHEN, Regina. **Pesquisa e projeto de espaços públicos: rebatimentos e possibilidades de inclusão da diversidade física no planejamento das cidades.** São Paulo, 2004.

DURAND, G. **A Bioética: natureza, princípios, objetivos.** São Paulo: Paulus, 1995, p.18.

FONTINELE JR., K. **Ética e Bioética em Enfermagem.** 2. ed. rev., atual. e ampl. Goiânia: AB, 2002, p.14.

GAIO, Roberta. **Para além do corpo deficiente**: histórias de vida. Jundiaí: Editora Fontoura,2006 p.26.

GARRAFA. Volnei. **Da bioética de princípios a uma bioética interventiva**. Revista de bioética e Ética Médica do Conselho Federal de Medicina – CFM. Brasília/DF. v.13, n.1, 2005, p.35.

PAGLIUCA .Lorita M.F.; ARAGÃO. Antônia E.de A ; ALMEIDA.Paulo .C. Acessibilidade e deficiência física: identificação de barreiras arquitetônicas em áreas internas de hospitais de Sobral, Ceará. Rev. esc. enferm. USP vol.41 no.4 São Paulo Dec. 2007.

REICH, Warren T. **The Word `Bioethics': The Struggle over Its Earliest Meanings.** Kennedy Institute of Ethics Journal, 1995, p.18.

ROY, David. **Orientations and tendencies in Bioethics (1970-1990).** San Francisco & London: International Scholars Pub, 1999, p.23.

SASSAKI, Romeu Kazumi. Inclusão: Construindo uma sociedade para todos. 3 ed. Rio de Janeiro: WVA,2003

ZOBOLI, E. L. C. P. **Bioética e atenção básica: um estudo de ética descritiva com enfermeiros e médicos do Programa Saúde da Família**. São Paulo, 2000, p.03.