

Bioethical conflicts in the training of professionals with disabilities

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Abstract

Disability presents a significant increase worldwide, mainly affecting vulnerable populations, such as young people, who have worse academic and health outcomes, compared with able bodied people. There are international conventions that guide the inclusion of students with disabilities, at the academic level and curriculum. This article analyzes the ethical conflicts that underlie the higher education training of professionals with disabilities in the area of health, particularly nursing, and who work in clinical environments where users require care quality. As a methodology, the bioethical analysis is proposed focused on the background review on disability – situation of bioethical conflict – and the proposal to address the conflict situation according to bioethical discernment. Important efforts are required at the level of educational policies to properly include students with disabilities at the higher education.

Keywords: Disabled persons. Bioethics. Higher education. Students. Nursing students.

Resumo

Conflitos bioéticos na formação de profissionais com deficiência

A deficiência apresenta um aumento significativo em todo o mundo, afetando principalmente populações vulneráveis, entre as quais se destacam jovens que apresentam os piores resultados acadêmicos e de saúde, em comparação a pessoas sem deficiência. Existem convenções internacionais que orientam a inclusão de estudantes com deficiência nos campos acadêmico e curricular. O objetivo deste artigo é analisar os conflitos éticos subjacentes à formação de profissionais do ensino superior portadores de deficiência, que estudam na área da saúde, particularmente na área de enfermagem, e trabalham em ambientes clínicos onde os usuários necessitam de cuidados de qualidade. Como metodologia, propõe-se a análise bioética com foco na revisão dos antecedentes da deficiência – situação de conflito bioético – e a proposta de enfrentar a situação de conflito segundo o discernimento bioético. São necessários esforços importantes ao nível das políticas educacionais que incentivam a inclusão dos estudantes com deficiência no ensino superior.

Palavras-chave: Pessoas com deficiência. Bioética. Educação superior. Estudantes. Estudantes de enfermagem.

Resumen

Conflictos bioéticos en la formación de profesionales con discapacidad

La discapacidad presenta un incremento significativo en todo el mundo, afectando principalmente a poblaciones vulnerables, como la de los jóvenes, que presentan peores resultados académicos y de salud en comparación con personas sin discapacidad. El objetivo del artículo es analizar los conflictos éticos que subyacen a la formación de estudiantes con discapacidad del área de la salud, particularmente en enfermería, que realizan prácticas en escenarios clínicos en donde los usuarios requieren cuidados de calidad. Como metodología se propone el análisis bioético de una situación de conflicto. El artículo concluye que es necesario desarrollar políticas que incluyan a los estudiantes con discapacidad en la educación superior.

Palabras clave: Personas con discapacidad. Bioética. Educación superior. Estudiantes. Estudiantes de enfermería.

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According to the 2011 World Report on Disability, there are more than one billion people in the world living with some form of disability, which is about 15% of the global population^{1,2}. In this report, the World Health Organization (WHO)³ also points out that disability mainly affects vulnerable populations, being more common in women, older adults, children, and poor adults.

According to the WHO³, people with disabilities have poorer health and educational outcomes compared to people without disabilities. Additionally, they have lower economic participation and higher poverty rates. These results are attributed to difficulties in accessing basic services such as health, education, employment, transportation, and information (difficulties that are particularly accentuated in disadvantaged populations).

Disability is a condition experienced by the human being in a complex manner, thus the development of interventions to overcome disadvantages are multiple, systemic, and vary according to the context³. In this regard, the Convention on the Rights of Persons with Disabilities (CRPD), adopted by the United Nations in 2006, aims to *promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity*⁴. Disability is part of the human condition, and most people may suffer some kind of transitory or permanent disability at some point in their lives, making them vulnerable and with special needs³.

The vulnerability and dignity of people with disabilities that the United Nations proposes to consider are aspects that have also been described as principles of bioethics⁵. Authors such as Torralba Roselló⁶ state that vulnerability is the principle most closely linked to the fragility of people. A vulnerable human being, says the author, is a fragile being, whose integrity may be constantly threatened by external and internal reasons. A person with a disability becomes a vulnerable being, dependent and limited in their actions, without the possibility of being absolutely self-sufficient. Under this condition, vulnerable people are affected in all dimensions of their lives.

Torralba Roselló⁶ defines dignity as an attribute or characteristic of the person and argues that recognizing it implies relating it to respect. Dignity is not a physical or natural attribute, but something that is predicated on being, by the mere fact of being a person. Dignity is part of the human condition, thus *affirming the dignity of a person means that it cannot be violated, nor can it be treated in an inferior manner to its ontological category*⁷.

Considering the above and that disability is a condition in which people experience vulnerability, loss of autonomy and integrity, it is imperative to create environments that reduce these conditions and promote the dignity of people as an essential human right. Using the method of bioethical discernment, this article analyzes ethical conflicts that underlie the training of students with disabilities in the health area, particularly in nursing, who work in clinical environments where users require quality care.

The article is divided into three sections: a first section describing the background and main concepts involved in disability in higher education; a second section that addresses a conflict situation in the academic environment – specifically in nursing– that requires a bioethical approach; and a third section with a proposal to solve the conflict situation using bioethical discernment.

Background on disability in higher education

Disability in the world and in Chile

The International Classification of Functioning, Disability and Health (ICF) defines disability as a general term that encompasses impairments, activity limitations and participation restrictions³. Disability, according to this definition, denotes negative aspects that occur in the interaction between people who have a health problem (such as cerebral palsy, Down syndrome or depression) and personal and environmental factors (such as negative attitudes, inaccessible transportation and public buildings, or lack of social support).

According to the WHO World Report³, the number of people with disabilities is growing,

which is mainly due to the aging of the population, since older adults are at greater risk of disability as physical, biological, psychological changes take place. The characteristics of disability, however, vary according to the country and are influenced by health problems such as traffic accidents, cancer, chronic and cardiac diseases, conflicts, bad eating habits and substance abuse. Regarding health problems, traffic accidents sometimes result in physical disability, mainly in young people or young adults. This age group has the highest risk of suffering this type of injury, differently from older people, who face hearing, visual and physical difficulties.

The WHO report also comments on the stereotypical views of disability, such as those *insisting on wheelchair users and some other "classic" groups such as blind or deaf people*⁸. Thus, it is described that people with physical impairments experience disadvantages more frequently, revealing a condition of inferiority that affects social interaction and the performance of social roles.

Insufficient policies and regulations, negative attitudes from society, problems with service provision, insufficient funding, lack of accessibility, lack of consultation and social participation, and lack of data and evidence on disability^{2,3} are among the main difficulties faced by people with disabilities, acting as barriers that contribute to social exclusion. In some cases, opportunities to access services only appear when people with disabilities insistently demand them, under the protection of their country's legislation.

Because of these difficulties, people with disabilities are affected in health outcomes, academic and economic participation, with higher rates of poverty, higher dependency and lower social participation⁹. Regarding schooling, children with disabilities are less likely to enter and remain in school. School failure is present in all age groups and countries, but especially in low-income countries³.

Disability involves complex aspects, which not only produce physical barriers, but also social barriers, being up to society to provide conditions to overcome these barriers¹⁰. Thus, this article is based on the social model of disability^{11,12}, which, beyond functionality,

considers the limitations that society itself imposes on the person with a disability¹³. From this perspective, disability is defined as *the disadvantage or restriction of activity caused by the contemporary social organization that does not consider, or insufficiently considers, people with functional diversities, and therefore excludes them from participation in the current activities of society*¹⁴.

There are documents that propose specific rights for persons with disabilities, including the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993), by which the United Nations (UN) undertook the obligation to ensure the rights of persons with disabilities¹⁵. For their part, the participants of the Conference on Special Educational Needs: Access and Quality, held in 1994 in Spain, undertook the task of making special educational needs more visible. In Chile, in 1994, the National Congress passed Law 19.284¹⁶, establishing norms for the full social integration of people with disabilities¹⁰.

In 2006, the UN approved the Convention on the Rights of Persons with Disabilities¹⁷, based on human rights and conceived as an instrument of social development of the signatory States, which committed themselves to fight prejudice and stereotypes and to promote awareness of the capabilities of persons with disabilities². Among the principles of this convention are: *a) respect for inherent dignity, individual autonomy, including the freedom to make decisions, and independence; b) nondiscrimination; c) full and effective participation and inclusion in society; d) respect for difference and acceptance of people with disabilities as part of the human condition and diversity; e) equal opportunities; f) accessibility*¹⁸. Based on this, we can argue that the social model is consistent with the values that underpin human rights: dignity, freedom understood as autonomy and equality of all human beings¹⁵.

Regarding education and disability aspects of this article, the convention establishes that *States Parties should ensure to persons with disabilities general access to higher education, vocational training, adult education and lifelong learning, without discrimination and in equality with others. To this end, States Parties shall ensure reasonable*

modifications for people with disabilities¹⁹. These adjustments consider the incorporation of innovations, curricular adaptations and infrastructure, as well as training and awareness for inclusive education^{2,10,15}. In this sense, in countries such as Spain, there was significant progress in terms of educational inclusion²⁰. The same thing happened in some Latin American countries where the efforts to achieve inclusion in higher education are focused on analyzing the conditions and developing concrete actions^{20,21}.

In 2010, Chile passed the current Law 20.422²², establishing the Rules on Equal Opportunities and Social Inclusion of Persons with Disabilities and creating the National Disability Service (Senadis - *Servicio Nacional de la Discapacidad*), under the Ministry of Social Development. The National Policy for the Social Inclusion of Persons with Disabilities was also drafted based on this law (2013-2020)²³. Article 5 of Law 20.422 defines a person with a disability as *a person with one or more physical, mental, psychological, intellectual or sensory impairments, temporary or permanent, whose interaction with various environmental barriers prevents or restricts his or her full and effective participation in society, on equal conditions with others*²².

Disability in education in Chile

In Chile, the Second National Disability Study, sponsored by the World Bank and the WHO, conducted in 2015, revealed that 20% of the population aged 18 years or older (2,606,914 individuals) lives with a disability¹⁰. Regarding the level of schooling, the report showed that 7.4% of adults with disabilities have no formal education, 23.4% have incomplete basic education, 16.1% complete basic education, 14.7% incomplete secondary education, 23.4% complete secondary education, 5.9% incomplete higher education and only 9.1% complete higher education¹⁰.

Currently, Chilean legislation, by Law 20.422, states that *the access of persons with disabilities to an inclusive educational system with equal opportunities at all levels, from Kindergarten to Higher Education, characterized by the incorporation of innovations and curricular and infrastructure adaptations, with teachers who are sensitized, trained and professionally trained*

*in inclusive education, must be ensured. Likewise, the disability variable should be considered in the periodic monitoring systems and instruments aimed at improving the quality standards of the educational system*²².

Article 39 of the law establishes that higher education institutions must have mechanisms in place to facilitate access for persons with disabilities, as well as to adapt study materials and teaching aids so that such persons can access the different courses²².

In 2011, a study by the Ministry of Education showed that, of 174 institutions asked about whether they had adaptive systems to receive students with disabilities, only 75 institutions answered the survey. Of these, 15 universities from the Council of Rectors of Chilean Universities (out of a total of 25), 16 private universities (35 in total), 15 professional institutes (43 in total) and 15 technical training centers (75 in total) answered affirmatively¹⁰. Regarding students with disabilities, 637 were studying in the universities of the Council of Rectors (256 with motor disabilities, 210 with visual disabilities and 43 with hearing disabilities), 92 in private universities, 89 in professional institutes and 25 in technical training centers. Their main areas of study were humanities and health, divided into pedagogy, social work, psychology, law and nursing¹⁰.

Inclusion of people with disabilities in nursing education

There is a diversity of perspectives on inclusion in nursing education. On the one hand, although there is an increase in the prevalence of disability, this condition receives little attention in the disciplinary training²⁴. On the other hand, the issue of disability in nursing students has been a topic of interest for decades^{25,26}. In 2004, a study showed that the number of students with disabilities in United States higher education nursing programs was increasing²⁵. The study highlighted the ethical and legal obligation to provide education to individuals with disabilities, noting that their entrance in educational programs intensified after 1990, with the approval of a law on the theme in the country. However, nursing students

with disabilities continue to face barriers such as stereotypes and discrimination, as they are often seen as professionals without the necessary skills to provide safe, comprehensive and quality care, according to the needs patients may have^{25,27,28}.

Internationally, nursing schools have little experience in incorporating students with disabilities²⁵, although there is a positive disposition to receive them²⁹. This situation also occurs in Chile, where, although legislation promotes the inclusion of students with disabilities in higher education, reality shows that adjustments are still required for full inclusion, through the creation of spaces and opportunities for young people who wish to study.

Changing programs is a real need, and this change includes modifying institutional policies, forming special teams, providing tutors, and reforming institutional units^{25,30,31}. People with disabilities can perform the same tasks as people without disabilities, but using different methods than the traditional ones, implying institutional adjustments. Adapting nursing programs could be considered the basis for facilitating access and helping to integrate people with disabilities in the profession²⁵. In this regard, a positive example is that of the National Organization of Nurses with Disabilities in the United States. The entity supports the recommendation to accept more people with disabilities to study nursing and at the same time fights for the elimination or modification of the functional skills criterion used for admission to nursing schools, since it restricts access possibilities³¹.

Inclusion is based on offering education to students indiscriminately, providing them with an education capable of identifying the needs of all (whether they have an impairment, disability or require curricular adaptation), so they can learn and develop as individuals^{26,29-31}. Some authors argue that strategies such as the preparation of teachers and the existence of tutors are fundamental in inclusive education^{27,29}. They also suggested that positive attitudes towards students with disabilities are an important quality of professionals, combined with ethical responsibility. It is recommended that the team of professionals promote cooperative relationships

between students with and without disabilities, facilitating interaction between them²⁷.

The inclusion of students with disabilities in nursing schools is a process that must occur intentionally to promote the development of the university community^{28,31}. The objective is to favor the educational conditions of those who are more vulnerable, considering that people with disabilities, as Foucault states, are still considered "abnormal"³².

Bioethical perspective on ethical conflict in the academic environment

In the clinical context, research suggests different ways of approaching bioethical issues. In this regard, the proposed methodologies in bioethics or clinical ethics are based on processes that are mainly developed in two phases or moments: the analysis of the facts and the normative phase, or decision-making phase³³. Case studies of authors such as Beauchamp and Childress, who address ethical dilemmas through the application of four principles of biomedical ethics (autonomy, non-maleficence, beneficence and justice), stand out.

The deliberative method proposed by Diego Gracia, using the analysis of values and the definition of possible courses of action, also helps deal with situations of ethical conflict⁵. Authors such as Beca Infante³³ propose methods for ethical analysis synthesizing other methodologies, such as those of Diego Gracia and Albert Jonsen, to systematize facts and values, deliberate courses of action and define duties. The author establishes the dignity of the human being as an ethical framework, considering the circumstances and consequences of decisions. The method also includes the four principles of biomedical ethics according to the hierarchy proposed by Diego Gracia, who considers the principles of non-maleficence and justice as primary, and the principles of autonomy and beneficence as secondary.

Ethical conflict in the academic environment

The difficulty faced by students with disabilities in the development of activities that require movement or displacement can

be considered a situation of ethical conflict in the academic environment. Students with permanent physical disabilities find it difficult, in some cases, to perform basic activities related to movement, which can lead to dependence on others to carry out academic responsibilities. Disabilities that arise during the training process (as may occur with young people who enter school without a disability and acquire one when they enter university) are also situations that need to be addressed, considering the perspective of bioethics.

Some countries establish inclusion protocols with mechanisms to facilitate the participation of persons with disabilities as students in training. Such protocols allow students to enter, progress and complete their studies. However, in nursing schools, there are also more complex situations to deal with, particularly when students have to perform clinical practices involving other people or patients. It can be difficult to perform procedures in the manner required by the nurse's training for the people in need of care or health care.

Situations where it is difficult for students with physical disabilities to develop their clinical practice result in the need to review and evaluate the programs of nursing careers, where students have to achieve the competencies stated in their graduation profiles, linked to knowledge (cognitive), knowing how to behave (behavioral) and knowing how precede (procedural). The demands of nursing professional training occur primarily in clinical practice environments with the community, in the hospital, and are requirements that every student must meet to achieve the professional degree. However, an ethical conflict arises when students with disabilities are asked to perform caregiving activities in the same way as students without disabilities, as a requirement to obtain a professional degree.

In addition, another ethical conflict arises from the above, since patients need to receive quality care, both from health professionals and nursing students. In this regard, the legislation establishes that patients have the right to demand quality in the care and services they receive in the health system. Students must provide comprehensive care, according to the

needs of the patients, through the execution of adequate and adjusted nursing procedures, such as medication administration, injury care and monitor control.

Approach proposal

Based on what was proposed by Beca Infante³³, the two ethical conflicts described in the previous section are approached with the following outline: 1) description of the main ethical problem (description of the facts involved); 2) analysis of the ethical values and principles involved; and 3) identification of possible courses of action, rationale and recommendation.

Description of the ethical problem

The main existing ethical problem in the situation analyzed in this article is: Can higher education institutions and nursing schools to offer students with physical disabilities the possibility to develop their studies and complete their training to achieve the expected skills of a health professional, particularly a nurse responsible for providing timely and quality care, according to the individual needs of patients in the health system?

Analysis of the values and ethical principles implied

Identifying the main bioethical categories³⁴⁻³⁶ involved in the ethical conflict described requires considering three perspectives. First, the perspective of students with physical disabilities – who wish to study and complete their studies, and who are citizens with the right to be educated – including the bioethical principles of autonomy and justice. Second, the perspective of higher education institutions – specifically nursing schools, which have the ethical duty and responsibility to train a capable professional to meet people's health needs – including the ethical principles of non-maleficence and beneficence. Third, the perspective of the health system users – who have the right to receive care from qualified professionals who provide quality health

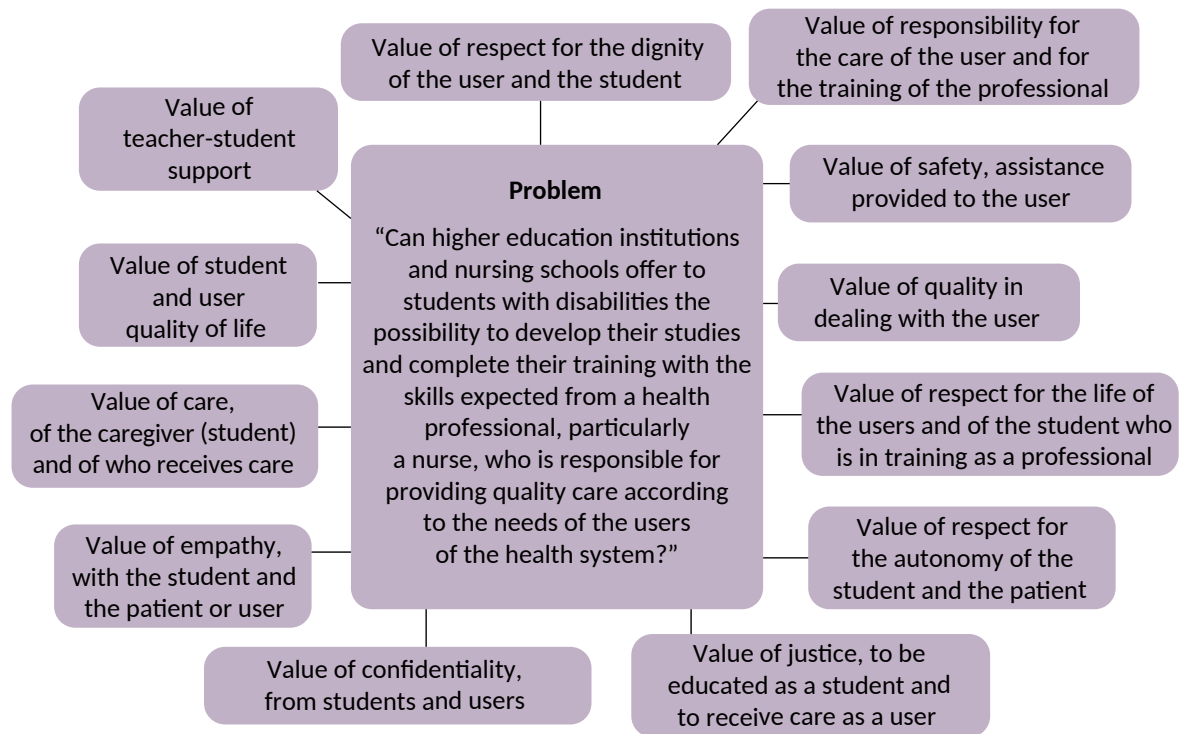
care – considering the ethical principles of justice, non-maleficence and beneficence.

According to the above and the proposed ethical-clinical analysis method³³, Figure 1 describes the values identified in the ethical conflict situation. These values were identified considering the particular case and the personal perception of the author, from her perspective as an academic of a higher education institution and a health professional. Based on the proposed analysis³³, various types of values are considered: physical, spiritual, aesthetic, intellectual, affective, economic, political and religious, among others, which are interrelated with the case analyzed. Derived from the values identified in Figure 1 are the principles of justice and non-maleficence, since students have the right to be treated fairly and to receive the same treatment by the higher education institution as other students without disabilities, being treated in accordance with

national and international public policies¹⁵. In addition, they have the right to complete their higher education, regardless of their physical disability. However, this principle contrasts with the principle of non-maleficence, since the user or patient also has the right to receive care from a professional who provides safe, quality service and guarantees a care free from physical harm.

Similarly, the principle of autonomy also conflicts with the principle of non-maleficence, since students have the right to complete their studies with autonomy, but this cannot always be ensured by higher education institutions, due to limitations for students with physical disabilities to have direct access to patients, to move independently and to perform necessary procedures. The institution must ensure effective achievement of minimum competencies that will enable students to provide quality patient care, free of harm.

Figure 1. Identification of values in ethical conflict of analysis



Update

Possible courses of action, principles and recommendations

Identification of possible courses of action

First: consider the principles of justice and autonomy, and that inclusion is part of human rights. Higher education institutions and nursing schools should make all curricular adjustments to allow students with physical disabilities to be trained and work as professionals¹⁵.

Second: considering the principle of non-maleficence, universities and nursing schools could restrict or limit access to health careers, since students with disabilities may not meet the graduation profile or may not develop the procedural competencies of learning in the same way as others. However, this course of action does not meet the expectations and definitions established by international conventions on inclusion.

Third: regarding the ethical conflict analyzed and considering the principle of non-maleficence, higher education institutions and nursing schools should make all curricular adjustments allowing the development of professional training according to the profile of students with disabilities, ensuring necessary skills and true inclusion.

Fourth: regarding the principle of justice, the higher education institution must be responsible for protecting the right of students with disabilities to receive fair treatment and equal rights, particularly to promote the principle of autonomy and to comply with the changes that are required not from these individuals, but from society, educating students without ignoring their differences.

Considering the four courses of action, this article proposes that the third and fourth courses are the most appropriate for solving the ethical conflict described.

Consistency of the chosen course of action

The course of action defined to solve the ethical conflict situation is supported by documents from international organizations and by Chilean legislation^{3,7,12}. Therefore, it is a recommendation that, besides being ethical, can be considered a legal requirement, which

allows it to be defensible in public, if demanded. Likewise, the chosen action, once applied, can be maintained over time, with the same bioethical foundation and principles: justice, beneficence, autonomy and non-maleficence.

Final considerations

Disabilities are increasing steadily over time, so the inclusion of people with disabilities must be present in all areas of life, considering the changes that must be generated under the social model of disability. Health and education are areas in which people with disabilities are more unprotected, or in a vulnerable condition, and therefore a permanent evaluation of their particular situation is required. For this reason, a large number of instances have been generated, starting with international organizations such as the UN, to promote the inclusion of people with disabilities based on human rights.

In addition to UN initiatives, Chilean legislation includes regulations and policies that favor the integration of students with disabilities in higher education, so that they can achieve a full life, particularly after becoming professionals. These regulations promote fundamental bioethical principles, such as autonomy and justice. Respect for the dignity of students, as human beings, is also a principle promoted by the legislation and should be incorporated by higher education institutions to facilitate inclusion.

But the entry of people with disabilities into higher education is not exempt from situations in which internationally declared bioethical principles are violated. There are still conflicts that remain to be fully resolved, even with respect to the current curriculum of university education. There are emerging efforts focused on addressing disability, however such efforts require substantial and permanent changes, supported by educational policies that consider the individual needs of students with disabilities, particularly in health careers. For now, there is a lack of concrete guidelines on how to train health professionals with disabilities, and this is an ethical dilemma that requires ongoing analysis. Inclusion policies exist, but their implementation requires some years.

The article analyzed a situation of bioethical conflict in the academic environment based on a working methodology that proposes courses of action for decision-making. It reflected on the process of deliberation, elaborating recommendations that consider the fundamental principles of bioethics. Based on this analysis and on the literature on the topic of inclusive education, we conclude that adjustments are needed in the nursing curriculum, so that intervention strategies that respect the human dignity of students with disabilities can be available.


In addition, institutional policies are required to generate changes based on the awareness of all members of the university community. These changes need to involve a bioethical perspective, since universal declarations of human rights, which are present in most current higher education regulations, are closely linked to bioethical principles. Academics who train nursing professionals are also required to have training and education to make changes in the curricula and to consider students with disabilities from an ethical perspective, bearing in mind their particularities as human beings.

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