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Precautionary Guarantees of the Right to Work for People with Catastrophic, Terminal, and Rare Diseases in Ecuador

Garantías Precautelares Del Derecho Al Trabajo Para Las Personas Con Enfermedades Catastróficas, Terminales Y Raras En El Ecuador

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Abstract

In Ecuador, catastrophic diseases are recognized within the Constitution as part of the Priority Care Groups, ensuring specialized care in both the public and private sectors for affected individuals. The aim is to protect the right to health and work comprehensively. However, the labor situation in Ecuador poses challenges. While the unemployment rate has decreased, there has been an increase in informal employment and non-full-time jobs. Currently, there is no legal instrument that explicitly links the right to work with the condition of individuals with catastrophic diseases. This study was conducted in Guayaquil, Ecuador, with the general objective of proposing modifications to the current regulations to safeguard the right to work for people with catastrophic diseases in Ecuador. The research analyzed existing regulations, judicial precedents, and international recommendations related to the right to work for individuals with catastrophic diseases. It explored the implementation of existing mechanisms and identified possible gaps in realizing this right for this group. Through expert criteria and assessment instruments, the research yielded results confirming the identified problem, allowing for the establishment of a proposal for reforms to the Labor Code.

Keywords: Catastrophic illnesses, right to work, right to health, job access and stability

Resumen

En Ecuador, las enfermedades catastróficas son reconocidas dentro de la Constitución en los Grupos de Atención Prioritaria y garantiza atención especializada tanto en el ámbito público como privado para estas personas e intentan proteger el derecho a la salud y al trabajo de forma integral, sin embargo; la situación laboral en Ecuador presenta desafíos. Aunque la tasa de desempleo ha disminuido, ha habido un aumento en el empleo informal y en empleos no plenos y, no existe un instrumento jurídico que relacione expresamente el derecho al trabajo con la condición de las personas con enfermedades catastróficas. Este estudio se llevó a cabo en Guayaquil, Ecuador, e implantó como objetivo general el realizar una propuesta de modificación a la normativa vigente que

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precautele los derechos al trabajo de las personas con enfermedades catastróficas en el Ecuador; analizó la normativa, precedentes judiciales y recomendaciones internacionales relacionadas con el derecho al trabajo para personas con enfermedades catastróficas. Se exploró la implementación de mecanismos existentes y se identificaron posibles brechas en la materialización de este derecho en este grupo; y a través de instrumentos de valoración como el criterio de expertos, se obtuvo un resultado que confirmó el planteamiento del problema lo que permite establecer una propuesta de reformas al Código Laboral.

Keywords: *Enfermedades catastróficas, derecho al trabajo, derecho a la salud, acceso y estabilidad laboral*

Introduction

The term "catastrophic diseases" refers to serious and highly fatal medical conditions that can have a significant impact on an individual's life and society as a whole. These diseases are typically severe, progressive in nature, and may require complex and costly treatments. The treatment and care for catastrophic diseases often come with a high price tag, affecting both patients and their families and communities.

In Ecuador, the Constitution of the Republic, in Article 35, recognizes this condition within Priority Care Groups and mandates that individuals with catastrophic diseases receive specialized care in both the public and private sectors. This can be interpreted as granting special treatment to people with catastrophic diseases due to their high-risk situation.

Another right outlined in the Constitution of the Republic of Ecuador is the right to health and work. Health, according to Article 32, is a right guaranteed by the State and can be linked to other rights related to human dignity. Therefore, comprehensive public policies must be implemented to materialize the guarantee of this right.

Regarding work, Article 33 attributes it not only as a right but also as a social duty and an economic right that allows individuals to achieve both personal and social fulfillment. Work is considered a productive role in contributing to the community.

When mentioning the right to work, it is essential to ensure its effective implementation. However, the political, social, and economic conditions operationalized by the State can result in the ineffective fulfillment of this right within the population.

In Ecuador, according to the National Institute of Statistics and Censuses (INEC) until the second quarter of 2023, the unemployment rate decreased by 0.5%. However, with a comprehensive evaluation, an increase in informal sector hiring can be observed. The informal sector refers to jobs or economic activities carried out independently, without a formal relationship with a company or employer (INEC 2023).

These activities often involve individual entrepreneurship or small businesses that are not registered or regulated by authorities. Workers in the informal sector lack the labor benefits and protections typically enjoyed by those in the formal sector. Informal activities may include street vending, domestic work, and subsistence agriculture, among others.

Additionally, another growing labor sector is the category of non-full-time employment, which refers to situations where workers do not have access to full-time employment with all corresponding labor rights and benefits. Individuals in non-full-time employment face

precarious labor conditions, either because they work fewer hours than expected, have temporary or informal contracts, lack access to social security, or have job instability.

Non-full-time employment can be seen in sectors such as informal trade, the informal economy, self-employment, or hourly employment. In these situations, workers often receive low pay, few labor guarantees, and limited professional development opportunities.

By reviewing the data issued by INEC, it can be added that there are categories with little emphasis, such as access to data on the percentages of people with disabilities linked to the labor sector, which face difficulties. There is also no category of data for individuals with catastrophic diseases related to the labor market.

Considering all these mentioned factors, it becomes apparent that predominant components are hindering the realization of the right to work for people without complex medical conditions and high risks. This indicates that for people with catastrophic diseases, having a calamitous condition with high economic costs poses an additional challenge to accessing decent and stable employment.

To address this issue, the State has developed mechanisms to protect the right to health in the workplace. However, even with positive rights recognizing these situations, there is no legal instrument explicitly linking the right to work with the condition of people with catastrophic diseases.

To conduct this study, the city of Guayaquil, Ecuador, was selected, where samples were taken to apply an exploratory investigation, and a preliminary approach to the object of the study was carried out with people with catastrophic diseases.

A detailed analysis of relevant regulations was conducted, along with a review of judicial precedents and recommendations from international organizations related to the right to work for people with catastrophic diseases. The feasibility of existing mechanisms for guaranteeing and realizing this right in this group was also examined, allowing the identification of possible gaps or deficiencies in its implementation. In light of these reviewed data, the following research question arises: Are there guarantees that safeguard the right to work for people with catastrophic, terminal, and rare diseases in Ecuador? Therefore, the objective of this study is to propose modifications to the current regulations to safeguard the rights to work for people with catastrophic diseases in Ecuador.

Materials and Methods

2.1. Methodology

Approach: The research adopts a mixed approach that enables an understanding of the social phenomenon of terminal or catastrophic illnesses and their impact on labor relations. Additionally, it quantifies the dimensions of the variables "right to work" and "catastrophic illnesses" to ensure greater objectivity in the inferences about the results.

Scope: A descriptive-explanatory-propositional scope was chosen, as it described the fundamental aspects of the manifestation of the problem of labor rights in people with catastrophic and/or terminal illnesses. It explained a set of factors affecting this social reality and proposed a normative modification aimed at solving the problem.

A non-experimental cross-sectional design was used, allowing the observation of the

phenomenon at a specific moment as it occurs in reality without manipulation of any of its variables.

2.2. Methods

Empirical Level Methods

1. **Observation Method:** Provided access to the understanding of the regularities and manifestations of the right to work in people with catastrophic illnesses.
2. **Literature Review Method:** Enabled the exploration of theoretical foundations and the analysis of norms and statistical results.
3. **Expert Criteria Method:** Used for the validation of the normative modification proposal.
4. **Measurement Method:** Employed for measuring the dimensions resulting from the operationalization of variables through the application of instruments.

2.3 Theoretical Level Methods

1. **Deductive-Inductive:** It is necessary to start from the concept of what a catastrophic illness is to understand the health and life situation of people who suffer from them, and how they can carry out their work activities based on their health condition, with the state's protection as a prioritized group.
2. **Analytical-Synthetic:** The main constitutive elements of social responsibility, the protection of the Ecuadorian state, the adaptation of means to the needs of this population, and the creation of regulations or mechanisms that facilitate their right to work and lead a dignified life were analyzed.
3. **Historical-Logical:** To systematize the impact of job stability for people with catastrophic illnesses over a specific historical period and its evolution.
4. **Lege Ferenda Method:** Used to determine the coherence between the social context and legal dogma justifying the right to work for people with rare and catastrophic diseases in Ecuador.

2.4. Data Processing Methods: The non-parametric statistical method was used, which provided the process of tabulation and treatment of the information collected as a result of the application of the instruments.

2.5. Technique and Instruments

- a) **Document Review Guide:** To systematize the literature review processes and statistical analyses that supported the theoretical framework of the research.
- b) **Observation Guide:** Helped define the regularities of the phenomena contained in the variables: constitutional principles, and guarantee of labor rights for people with catastrophic illnesses.
- c) **Interviews:** Conducted with legal professionals with expertise in labor and constitutional law.
- d) **Expert Criteria:** Used for the validation of the proposal related to the modification of the norm.

2.6. Determination of Population and Sample

For the determination of the study sample, the data from the Executive Coordination of the Research and Defense Center for the Right to Work (CIDDT) of Ecuador were considered. The CIDDT records 265 lawyers handling labor cases in the city of Guayaquil. From this

population, a sample of 60 legal professionals was selected using a sampling technique known as purposive or judgmental sampling at the investigator's convenience (Pérez-Luco & others, 2017). This method is not based on randomness, as in other sampling systems; the choice of who is included in the sample depends on the investigator's decision to generalize to the entire population. Three relevant selection criteria were used for decision-making:

1. Professional experience
2. Scientific activity
3. Academic level

Results

For the analysis of the perception of this issue, interviews were conducted with 60 legal professionals in the city of Guayaquil. To determine this purposive sample, academic level, scientific publications, and experience in teaching and professional activities were taken into account.

Next, a detailed analysis of the results is carried out for each of the criteria expressed through open-ended questions, in line with the indicators obtained from the operationalization process of the variables.

Question 1: Do you know what catastrophic diseases are and what consequences they generate?

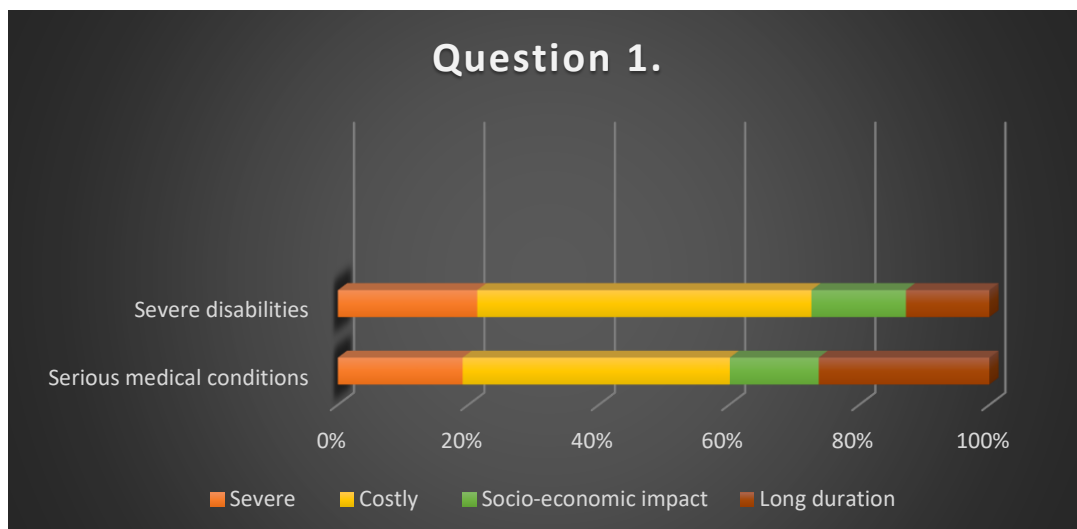


Figure 1: Measurement of the First Question of the Survey Applied to Labor and Constitutional Law Experts.

Source: Interview with Legal Experts (2023). Own Elaboration.

In the first question, it can be observed that out of the total interviewees, 61% agree that catastrophic diseases are severe medical conditions with significant repercussions, while 39% attribute them to severe disabilities. In a brief analysis, it is concluded that in both groups of definitions from the interviewees, they attribute 18% and 19%, respectively, to catastrophic diseases being characterized as severe. However, there is a marked difference in that the experts who define catastrophic diseases as severe disabilities incur higher financial costs compared to the group of people who consider them as severe medical conditions, and they lean towards them being of long duration. With these results, it can be inferred that the experts have a comprehensive understanding of the definition of catastrophic diseases and their

consequences, both personally for the affected group and their families and society.

Question 2: Do you consider that there is a precaution in the Labor Code for people with catastrophic, terminal, and rare diseases?

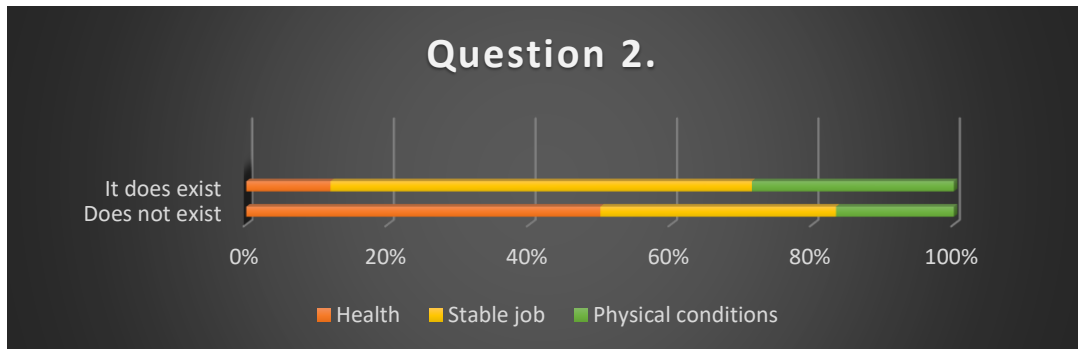


Figure 2: Measurement of the Second Question of the Survey Applied to Labor and Constitutional Law Experts.

Source: Interview with Legal Experts (2023). Own Elaboration.

In the assessment of the second question, 70% of the interviewed experts said that there is no safeguarding of the right to work for people with catastrophic diseases, while 30% responded that there is protection for the right to work for people with this medical condition. Of the 60% in the majority group who answered that there are no measures to safeguard the labor rights of this community, they focused on the scarcity of stable employment accompanied by a lack of suitable physical conditions for the adaptation of individuals with calamitous diseases. In contrast, 49% of the affirmative responses focused on safeguarding the right to work for people with tragic diseases through a specialized healthcare system. Based on these criteria, it can be inferred that experts envision a precarious situation when it comes to safeguarding the right to work for people with catastrophic diseases; therefore, the author argues that there is no exclusive labor rights protection for individuals with severe and grave medical conditions.

Question 3: To what extent is there coherence with constitutional principles and the regulation that the Labor Code establishes to protect the rights of people with catastrophic diseases in order to uphold their right to work?

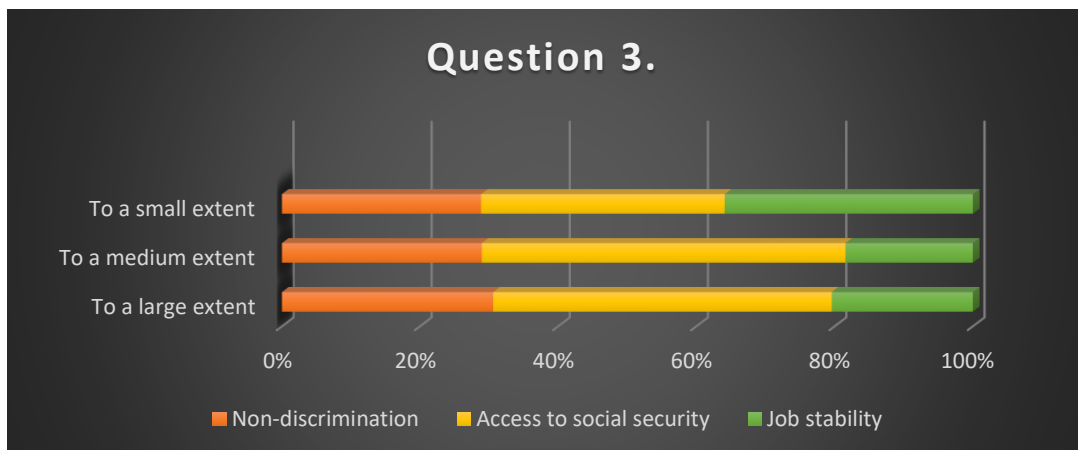


Figure 3: Measurement of the Third Question of the Survey Applied to Labor and Constitutional Law Experts.

Source: Interview with Legal Experts (2023). Own Elaboration.

From the assessment of the third question, the interviewed legal professionals agreed that 52% believe there is to a small extent coherence between constitutional principles and the Labor Code regarding the protection of labor rights for people with catastrophic, terminal, and rare diseases. On the other hand, 32% argue that there is to a moderate extent a coherent relationship between constitutional principles and the labor code, and finally, 16% claim that there is to a large extent coherence between the Constitution and the Labor Code.

In the first group, which attributes the limited relationship between the Constitution and the Labor Code for safeguarding the rights of people with catastrophic diseases, they point out that job stability is a prominent cause of the lack of correspondence between both regulations. Conversely, the two groups claiming a correlation between the mentioned regulations focused on the characteristic of access to social security. In an analysis conducted by the author, it is inferred that the majority of experts do not consider there to be a harmonious relationship when applying the right to work for people with catastrophic diseases, as specialized legislation is superficial regarding the exclusive protection of this vulnerable group.

Question 4: Do you believe there is a connection between the social demand expressing the need to protect the labor rights of people with catastrophic diseases and the Ecuadorian legal system?

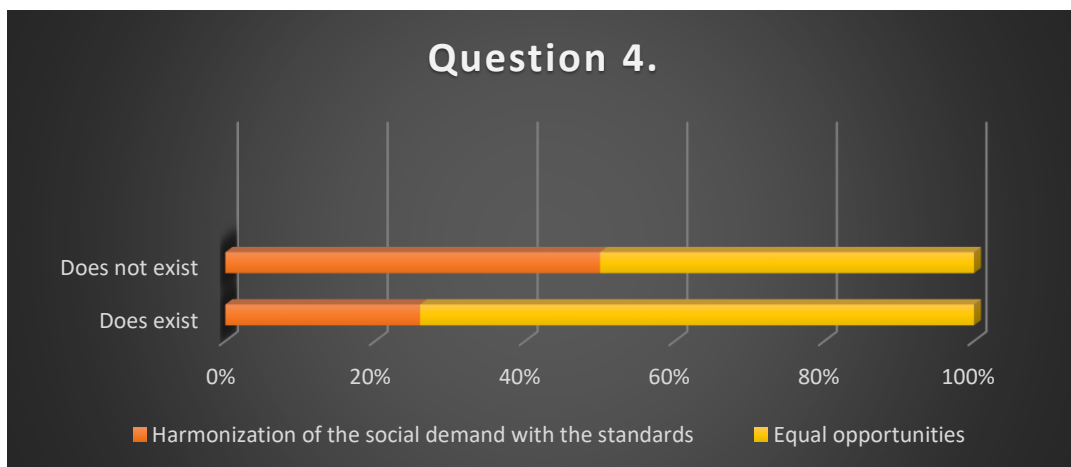


Figure 4: Measurement of the Fourth Question of the Survey Applied to Labor and Constitutional Law Experts.

Source: Interview with Legal Experts (2023). Own Elaboration.

In the assessment of the fourth question, 83% of the consulted experts indicate that there is a relationship between the social demand expressing the need to protect the labor rights of people with catastrophic diseases and the Ecuadorian legal system; however, 17% think otherwise. From the group that affirmed the existence of social demand, 75% state that the community requires a reaffirmation of equal opportunities for people with catastrophic, terminal, and rare diseases, while 25% believe that harmony should be strengthened between the social demand for the protection of the right to work for people with catastrophic diseases and the existing regulations.

Regarding the group that disagreed with the affirmative answer regarding the existence of social demand, they consider equally that there is no need to establish regulations affirming equal opportunities for people with catastrophic diseases. The author concludes that there is a strong social demand that requires comprehensive protection of the rights of workers with catastrophic medical conditions.

Question 5: In your opinion, what proposals could be introduced into the Ecuadorian Labor Code to protect the labor rights of those diagnosed with catastrophic, terminal, and rare diseases?

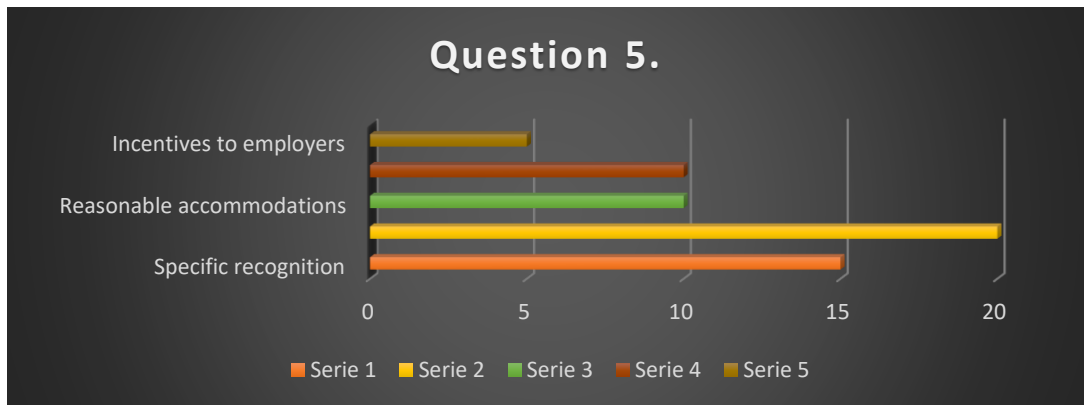


Figure 5: Measurement of the Fifth Question of the Survey Applied to Labor and Constitutional Law Experts.

Source: Interview with Legal Experts (2023). Own Elaboration.

In the evaluation of the fifth question, consideration was given to the coinciding responses since, being an open-ended opinion question, it provided an opportunity to express various points of view. 20% of the interviewees suggest that specific recognition in specialized regulations regarding the protection of the right to work for people with catastrophic diseases should be considered; 33% say that job stability for this vulnerable sector should be reinforced, 15% point out that reasonable accommodations should be implemented to allow people with catastrophic diseases to operate in a friendly environment, 18% opted for the suggestion of special leave for this vulnerable group to protect their job integrity, and 14% recommend that employers be incentivized to hire people with these types of medical conditions.

The author considers it relevant and concludes that all the proposals from the experts are harmoniously related to expanding the coverage of labor rights for people with catastrophic, terminal, and rare diseases, allowing greater visibility for the realization of their rights.

3.1 Discussion

The schematization of the instruments applied in this research confirms that legal professionals agree that even though there are regulations that encompass the rights of people with catastrophic, terminal, and rare diseases, they do so only in a general manner with little emphasis on addressing this sector. This creates a significant impact on individuals with these medical conditions when exercising their rights.

After systematizing general and substantive theories with empirical references, the author highlights that the recognition of labor rights for people with catastrophic, terminal, and rare

diseases is still progressing slowly. This leads to stagnation in accessing the realization of this fundamental right for this group of individuals with dual vulnerability.

While the state seeks to provide appropriate guarantees, the lack of immediate solution mechanisms for the execution of this right necessitates resorting to judicial proceedings that prolong the processes. This results in physical, emotional, and socio-economic strain on individuals facing a disadvantaged situation, leading to the cessation of the struggle for their rightful rights and leaving them in a state of vulnerability.

Within the analysis of the assessment instruments that allowed access to the opinions of the experts (ANNEX 1), it was found that there is a comprehensive understanding of the need for specialized regulations to protect the labor and health rights of people with catastrophic medical conditions. The experts recommend covering fundamental aspects that safeguard the right to work of the mentioned group and providing incentives for employers who include this labor force in their workforce.

Therefore, the methodology applied to this study yielded optimal results for analyzing the researched topic. This allowed confirming that the hypothesis that the guarantees safeguarding the right to work for people with catastrophic, terminal, and rare diseases in Ecuador are insufficient coincides with the reviewed and studied background mentioned in this research.

Hence, the author proposes a modification to the Ecuadorian Labor Code (ANNEX 2), offering an effective alternative that inclusively protects individuals with catastrophic, terminal, and rare diseases. The proposal suggests adding specific aspects to the law to explicitly address the right to work for people with non-professional long-term illnesses.

Proposal

The proposal supports the modification of the Labor Code of Ecuador with the following wording:

Reform to the Labor Code

Article 1.- amend article 42, number 33, of the labor code: The public or private employer with a minimum of twenty-five employees is obligated to hire, at least, one person with a disability and one person with catastrophic, terminal, and rare diseases in permanent positions that are considered appropriate based on their knowledge, physical condition, and individual abilities, observing the principles of gender equity and diversity of disability. This obligation shall be fulfilled in the first year of the validity of this Law, counted from the date of its publication in the Official Registry. In the second year, the hiring will be 2% of the total number of workers; in the third year, 4%; in the fourth year, 6%, until reaching the fifth year, where the hiring will be 8% of the total number of workers, and this fixed percentage will be applied in the subsequent years.

Article 2.- add to the labor code article 174 number 1, third subsection: Under no circumstances can a contract with an employee diagnosed with a catastrophic, terminal, and rare disease be terminated.

Article 3.- add to the labor code article 175 second subsection: The application of the estimated time in this article is excepted for individuals suffering from catastrophic, terminal, and rare diseases, given their condition of double vulnerability, in accordance with the Constitution of the Republic.

Article 4.- amend article 195.1 second subsection, regarding the prohibition of dismissal in

work contracts: The same rules regarding the ineffectiveness of dismissal will apply to union leaders in the performance of their functions for the period established in article 187 and will apply to individuals diagnosed with a catastrophic disease recognized by the Ministry of Public Health of Ecuador.

Article 5.- add article 200 subsection 3: The seizure of the reserve fund of a worker clinically diagnosed with catastrophic, terminal, and rare diseases is prohibited.

Article 6.- add article 48.1: Special working hours for workers with catastrophic, terminal, and rare diseases: Workers diagnosed with diseases classified as catastrophic by the Ministry of Public Health must have special working hours that do not affect their medical condition. The employer must assess all elements of the worker's record to adapt their working hours to their needs.

Validation of the Proposal

Expert Criteria for the Validation of the Proposed Regulatory Modification to the “Labor Code”

The expert criterion for the validation of normative modifications is an assessment technique based on the thorough review and evaluation of the proposal by individuals with high expertise in the specific thematic area. In the case of this research, the selection of specialists took into account: experience in the practice of labor law, relevant scientific activity supported by publications in indexed journals, academic activity related to the discipline, and the relevance of a fourth-level degree as competence indicators for the critical examination of the proposal (Fernández & López, 2014).

Criteria for assessing the competence of experts:

1. Experience in legal activities related to labor law
2. Publications relevant to labor law
3. Academic activity related to the discipline of labor law
4. Fourth-level education related to labor law or constitutional law

Tabulation of the results of the cognitive components of the experts on labor law (Kc).

Interviews were conducted with specialists to determine the extent to which the selected professionals met the requirements for the assessment role, yielding the following results:

$Kc = (\text{evaluated knowledge} \times 0.1)$

Table 1: Value of Competencies Per Expert.

Experts	Value of competencies per expert										Kc
	1	2	3	4	5	6	7	8	9	10	
1									X		0.9
2					X						0.5
3							X				0.7
4								X			0.8
5						X					0.6
6								X			0.8
7				X							0.4
8				X							0.4
Total 8											0.64

Source: Own Elaboration.

For the determination of the level of competencies of the experts (NCE), the totals of the values in the Kc column were added and divided by the number of experts, resulting in an average competency value of 0.64. Experts who scored below this average were excluded (experts 2, 5, 7, and 8), leaving only the four experts who achieved scores above the mean value (experts 1, 3, 4, and 6), as observed in the table.

Table of Evaluation by Experts of the Proposed Regulatory Modification

For the evaluation of the proposal, five indicators were established, and a Likert Scale of 10 levels was used as the reference value, where 10 represents the optimal value and 1 is the critical value. The experts assessed the modification based on the degree and capacity it has to meet the criteria's requirements.

Table 2: Expert Evaluation of the Criteria.

Expert	Consistency with the principles the Code	Correspondence with the Labor purpose of objectives it pursues	Level of applicability and adaptability in the context it regulates	Consistency with social demand	Extent to which the proposal optimizes the Labor	Mean value per expert
1	10	9	8	8	8	8.6
2	9	8	7	10	9	8.6
3	9	10	7	10	8	8.8
4	9	8	6	8	8	7.8
Mean value per criterion	9.25	8.75	7	9	8.25	8.45

Source: Own Elaboration.

To adapt the experts' results validation, this research based its assessment in correspondence with the studies of jurists Samuel Issacharoff and Geoffrey P. Miller (2018): In their work "Civil Procedure as Fairness," which contains a methodology already expressed in a previous study "Aggregate litigation come to Europe" (2009), where, in both cases, they used the Likert Scale to assess the perception of justice and fairness in the civil procedure system.

Consequently, with these previous observations for result analysis, the following validation criteria were predetermined:

Table 3: Value of the Resulting Criteria.

Average rating of less than 7	The proposal is unsatisfactory	Discard the proposal
Average rating from 7 to 8	The proposal is consistent	The proposal is applicable
Average rating from 8 to 9	The proposal is very consistent	The proposal is applicable with high consistency
Average rating from 9 to 10	The proposal has optimal consistency	The proposal is applicable and has optimal consistency

Source: Samuel Issacharoff and Geoffrey P. Miller (2018).

As a result of the validation criteria determination, it was established that the proposal: "modification to the labor code" has the condition of being applicable with high consistency, making the proposed normative modification viable. The high rating obtained by the experts in terms of coherence with the principles of the labor code (9.25) is significant, as well as the consistency that the specialists consider the proposal to have with social demand, justifying the legitimacy of the proposal.

Conclusions

Catastrophic diseases are severe and debilitating medical conditions that have a significant impact on the health and quality of life of those who suffer from them. These diseases are often chronic, either genetic or acquired, and are characterized by their serious and life-threatening nature. Examples of catastrophic diseases include certain types of advanced cancer, degenerative neurological diseases, severe autoimmune diseases, and rare genetic disorders.

These terminal health anomalies have a profound impact on the lives of the affected individuals, their families, and society as a whole. In addition to medical challenges, these diseases carry a significant emotional, financial, and social burden, underscoring the importance of policies and support measures to address these impacts.

In Ecuador, the recognition and application of the right to work for people with catastrophic diseases have been addressed through various measures and policies aimed at providing facilities and protection for this vulnerable group. Some of these facilities and approaches include adaptations in the workplace to allow people with catastrophic diseases to continue working effectively and certain regulations that enable them to maintain job stability. However, to materialize these rights, individuals often have to resort to lengthy judicial proceedings because there is no specific legislation directed at people with these types of medical conditions.

In the systematization of the investigative elements, both general and substantive theories, and empirical references, with the application of the appropriate methodology for this research, it is concluded that there is a general recognition of the rights to health and work for people suffering from some type of illness that limits their capabilities for work. This leads to the integration of people with disabilities and people with catastrophic diseases into the same group. It is worth noting that, although both conditions have similar characteristics, the treatment is not equally applicable.

After systematizing and contrasting the information obtained from this study with social reality, the author concludes that it is necessary to reform the Labor Code of Ecuador to more effectively include the protection of the right to work for people with catastrophic diseases. This assessment aligns with the hypothesis outlined in this research, providing a truthful and timely result for implementing a favorable change for the evolution of fundamental rights.

The proposed modification to the Labor Code, specifically to its articles 42, number 33; 48.1; 174, number 1, third paragraph; 175, second paragraph; 195.1, second paragraph; and 200, number 3, underwent validation by expert criteria, obtaining a consistency rating of 8.45, which, according to the scale proposed by Samuel Issacharoff and Geoffrey P. Miller (2018), indicates high feasibility of its application.

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