


INTRODUCTORY NOTES ABOUT THE RIGHTS OF PEOPLE WITH DISABILITIES IN THE CONTEXT OF THE COVID-19

NOTAS INTRODUTÓRIAS SOBRE O DIREITO À VIDA DAS PESSOAS COM DEFICIÊNCIA NO CONTEXTO DE COVID-19

NOTAS INTRODUTORIAS SOBRE EL DERECHO A LA VIDA DE LAS PERSONAS CON DISCAPACIDAD EN EL CONTEXTO DE COVID-19


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ABSTRACT:

The reflections presented in this article discuss the guarantee of the right to life for all, granted by the Brazilian State, recognizing the specificities of people with disabilities in the context of the Covid-19 outbreak. The research methodology analyzes public statements and notes from councils and entities of civil society that defend the rights of people with disabilities in the face of threats during a pandemic. It is observed that this population segment becomes more vulnerable to contracting coronavirus and its implications. The mobilization of civil society to defend the guarantee of the right to life and human dignity is highlighted.

KEYWORDS: Life; Right to life; Human rights; People with disabilities; Covid-19.

Introduction

In March 2020, the World Health Organization recognized persons with disabilities as a risk group for the contagion of COVID-19, among other reasons, due to the difficulties of this segment in maintaining social distance as they need the support of caregivers; the recurrence of pre-existing health conditions that aggravate the disease; and also barriers to accessing health services, including prevention measures (WHO, 2020).

The National Health Council (CNS), through Recommendation No. 31, of April 30th, 2020, also pointed out that this public may have a higher risk of contamination due to obstacles in the implementation of basic containment measures, such as sinks and washbasins without physical accessibility or the physical difficulty of persons with disabilities to do hand hygiene properly; obstacles to maintaining social distance due to additional support needs as they are in health institutions, therapeutic or inclusive residences, institutional reception services, in addition to assistance for daily activities;

the need to lean on objects to obtain information about the environment or for physical support; difficulty in accessing health services and public health information; pre-existing health problems; and the use of assistive technologies such as canes, crutches, and wheelchairs.

It occurs that, beyond the important biomedical aspects, the pandemic has left explicit a series of the precariousness of the conditions of life and the fragility of the net of social protection (SAUCERS, 2020; HARVEY, 2020). In the case of persons with disabilities, these situations are even more complex: "Persons with disabilities are among the most marginalized and stigmatized in the world, even under normal circumstances," said Jane Buchanan, of the international organization Human Rights Watch in the face of the pandemic.

Data from the 2010 Census (IBGE, 2012) shows that persons with disabilities are among the poorest sections of the Brazilian population as 46.4% of this public receive up to one minimum wage or have no income, and 29.1% have income between one and two minimum wages. In addition to these data, there is also the Continuous Benefit Conveyance (BPC), of charitable nature, with a constitutional provision in the amount of a minimum wage, serves 4,549,478 Brazilians, of whom 2,527,257 are persons with disabilities in extreme poverty, without conditions to provide for their maintenance or to have it provided by their family. This means an income equal to or less than a quarter of the minimum wage¹ (STOPA, 2019).

This article aims to analyze the guarantee of the right to life by the Brazilian State for persons with disabilities in the light of the Covid-19 context. It is important to situate the challenges that involve researching with prospective analysis, especially in crises that are still under development. Therefore, the proposal for these introductory notes, still unfinished, considering that the social processes analyzed do not present themselves definitively and move in the process of building our reflections.

The reflections presented here were built within the scope of the project "The implications of COVID-19 for social protection" developed by the Study and Research Group on Democracy, Civil Society, and Social Work at the University of Brasília. The

¹ In November 2019, Bill 55/1996 was approved by the Federal Senate, which raised the value of the monthly income of access to the BPC to half the minimum wage per capita. However, there was a veto by the President of the Republic. In March 2020, the veto was overturned by the National Congress and the expansion of the income requirement continued. The federal executive branch called the Federal Court of Accounts (TCU) to suspend the effects of the legislation on the grounds of increased expenses. An infringement of a fundamental precept was also filed before the Federal Supreme Court (STF) by the President of the Republic due to the budgetary and financial impacts involved.

methodological path consisted in the analysis of manifestations and notes published by councils and entities representing civil society for the defense of the rights of persons with disabilities in the face of threats that emerge in the context of confronting the pandemic, placing the legal framework that deals with the right to life in the Brazilian State.

The recognition of the right to life for persons with disabilities

The universality of the right to life in the democratic rule of law is a precept consolidated in modern times. Ramos (2018) affirms that the State has three duties in the scope of the protection of life: obligation of respect by its agents on the life of the population; guarantee obligation, which consists of preventing the violation of life by third parties; and guardianship obligation, regarding the maintenance of a dignified life.

Two real dimensions of this right are pointed out by Ramos (2018) to understand its materialization. The first one refers to its verticality, which analyzes life from fertilization to death. The other is horizontal and verifies the right to quality of life enjoyed by human beings. To the author, this dimension deals with "(...) protection of the right to health, education, social security benefits, and even a balanced environment, to ensure the right to a dignified life" (p. 594).

Branco (2018) points out that the right to life carries with it a guarantee in addition to being alive, as it is also an affirmation of dignified life. Thus, the importance of the need for state action to implement guarantees provided for in the legal framework is highlighted, covering the right to food, housing, health, education. Ensuring the right to human dignity includes maintaining a life in which the realization of rights includes material and immaterial dimensions. In summary, protecting life implies the guarantee of civil and political, as well as social, cultural, and economic rights. A set of legal norms that intend to guarantee a dignified life to human beings is present in the normative framework in force in Brazil.

In the Federal Constitution of Brazil, the inviolability of the right to life is recognized in the caput of article 5, according to which all are equal before the law, without distinction of any kind. It is a fundamental right, a precondition for the existence and exercise of all other rights. According to Moraes (2005), the affirmation of this right has a double meaning: the right to remain alive and the right to have a dignified life in terms of subsistence. There are many fundamental rights and guarantees protected under this article: gender equality, freedom of expression and

belief, work, association, property, legal protection, among others. It is a comprehensive list of fundamental rights, which start from the notion of a dignified life and unfold in specificities important for human development in society.

The expansion of new rules that recognize fundamental rights is guaranteed by the Federal Constitution itself when it states in the same article 5 that international treaties and conventions can integrate the country's regulatory apparatus. It is based on this precept that the International Convention on the Rights of Persons with Disabilities (CRPD), approved by the United Nations in 2006, brings a series of rights and guarantees aimed at maintaining actions for a dignified life for persons with disabilities. In Brazil, the document stands out for being the first international convention with constitutional status. Thus, it is superior to all infra-constitutional rules, enjoying the same hierarchy and preponderance as the Federal Constitution of 1988.

Ratified in Brazil by Legislative Decree No. 186/2008 and promulgated through Decree No. 6,949/2009, the CRPD reaffirms in art. 10 that "States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others." It is noted that the commitment assumed by Brazil, as a State-party to the Convention, corroborates the notion of the right to a dignified life defended by Branco (2018), as there is a clear need for the importance of guaranteeing material and substantial equality for persons with disabilities.

It is compelling to note that there are different perspectives for understanding this right. In the analysis of Dhanda (2008, p. 46), the recognition of the right to life by the aforementioned Convention points out the basic equality between all human beings. In this sense, "The right to life is an affirmation that the difference due to disability contributes to the wealth and diversity of the human condition and is not a deficit that needs to be eliminated". In addition to the act of staying alive, in the interpretation of Santana and Almeida (2014), the right to life includes the effective exercise of choices, that is, a full life. This signals a search to break with the history of silencing persons with disabilities, presented by the restriction of the manifestation of their will.

Besides, the Convention imposes on the Brazilian State the duty to guarantee the minimum existential, through which life develops fully and with equal opportunities. At this point, it is possible to state a relationship with art. 28:

States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

Within the national legal framework, the Brazilian Law of Inclusion (LBI) (Law No. 13,146/2015) deals with the right to life correlated to dignity: Art. 10 "It is up to the public authorities to guarantee the dignity of persons with disabilities throughout their lives". The right to life is, therefore, related to a series of other rights in the field of social protection and respect for the dignity and citizenship of persons with disabilities, corroborating the notion of the right to life that is concerned with spheres larger than simple existence, as that horizontal dimension pointed out by Ramos (2018).

And how to understand the right to life in the context of a pandemic such as the one we are currently facing? The atypical situation driven by the spread of the coronavirus affects the scenario of the search for guaranteeing the rights of persons with disabilities, who face several barriers in their daily lives. Both CRPD and LBI provide guidance to the government and establish that it is necessary to take all measures that are important to ensure protection in exceptional scenarios.

Risk situations and humanitarian emergencies are dealt with in art. 11 of the CRPD, which highlights the need for specific measures for situations of greater vulnerability:

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, *all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.* (emphasis added).

In the understanding of Moreira and Bernardes (2014, p. 82), this device emphasizes that persons with disabilities "are disproportionately affected in disasters, emergencies and conflict situations, due to the frequent lack of accessibility in evacuation procedures, in the response (including shelters, camps, and food distribution), and recovery efforts". In other words,

persons with disabilities are more susceptible to being abandoned in disaster situations, due to the lack of preparation and planning of the

government and other agents involved to deal with their specificities, and the lack of accessible facilities, services and transport systems (ibid).

The LBI reiterates this understanding of the responsibility of the public authorities for the protection and safety of persons with disabilities in situations of risk, emergency, or state of public calamity, relating it to the right to life. When recognizing the vulnerability of persons with disabilities, it is understood the need for actions that recognize their specificities and guarantee accessibility conditions and resources.

Art. 10 [...]

Sole Paragraph. In situations of risk, emergency, or state of public calamity, the person with disabilities will be considered vulnerable, and the government must adopt measures for their protection and safety.

In the case of health emergencies, the right to life is directly related to the right to health: "Art. 18 Comprehensive health care for persons with disabilities at all levels of complexity is guaranteed, through SUS, universal and equal access to it". In this sense, the legislation provides for the priority of assistance to persons with disabilities, with the purpose of protection and assistance in any circumstances, which is subject to medical assistance protocols in public and private emergency services, according to art. 9 of LBI. Cases of refusal, delay, or difficulties in hospitalization, and even when medical, hospital, and outpatient care is not provided to this public, they are treated as a crime punishable by imprisonment and fine.

In the pandemic scenario, the defense of the right to life becomes imperative in the face of the collapse of the health system and the need for professionals to carry out the so-called "Sophie's choice" among those who will have access to a place in the Intensive Care Unit or a mechanical ventilation equipment (LAVIERI, 2020). The disabled person, who already encounters barriers of access and inclusion in society, in the scenario of the pandemic, finds an even more critical situation.

The Covid-19 scenario and persons with disabilities

Considering the legal framework set out in the previous section, the reflections presented on guaranteeing the right to life of persons with disabilities in the Covid-19

scenario will be built on the mobilization of councils and civil society entities for the defense of rights disseminated through demonstrations and public notes.

First, it is important to consider that persons with disabilities are a heterogeneous group, including those with physical, mental, intellectual, or sensory impairments, who will interact with barriers in different ways. This is because even in situations of equal or similar disabilities, people have different limitations and different needs (TORRES, MAZZONI, MELLO, 2007). The recognition of human diversity becomes essential to guarantee conditions and accessibility to resources that provide everyone.

The context of the pandemic elucidates the relationship between guaranteeing the right to life and the right to health, with emphasis on access to services and treatments, including priority, as already provided for in legislation. In the United States, activists in the movement of persons with disabilities have denounced the abandonment of people with Down syndrome, cerebral palsy, and autism who did not have access to equipment because, supposedly, they have a slower recovery. The situation prompted the opening of inquiries at the US Department of Health on priority only for patients without disabilities. A similar situation was reported in the United Kingdom when the Daily Star newspaper reported the death of a woman with Down syndrome due to the coronavirus and questioned abandonment in the face of health protocols (VENTURA, 2020).

Given these complaints, in Brazil, different civil society entities expressed concern about the guidance of health authorities and the conduct of health professionals. Among them, there is the Brazilian Federation of Down Syndrome Associations (FBASD) that released the "Note in defense of life during the COVID-19 pandemic in Brazil" (FBASD, 2020). The document is concerned with the protocol, to be eventually adopted by the authorities and doctors, regarding the care of people with Down Syndrome or other disabilities, in the event of a decision on who should have priority in receiving intensive care when there is no possibility to absorb all demands.

In the Note, referenced in the legal framework of the Federal Constitution and the CRPD, there is a fear of possible denial of access to adequate medical care and mechanical ventilators for people with Down syndrome or other disabilities, without equal opportunities with other people. Thus, he emphasizes that "the life of persons with disabilities cannot be underestimated based on their functional capacity or "utility for society", nor "neglected in the face of low expectations and quality of life" (ibid, p. 2).

The document also clarifies the defense of life-based on the principles of "dignity inherent to all human beings, equal opportunities, non-discrimination and respect for the acceptance of persons with disabilities as part of human diversity and humanity" (ibid, p. 2) affirming that "The Brazilian State needs, at this moment of crisis, to demonstrate to what extent it values the right to life of its citizens with or without disabilities and is committed to recognizing everyone with equal dignity".

These principles listed in the note demonstrate the need to guarantee structural conditions for the materialization of the right to a dignified life. The performance of the State through public policies that manage to provide equal opportunities for persons with disabilities is an adequate path for the realization of the right to life, formally recognized, but which needs strong advances and strengthening from a concrete point of view.

In Rio de Janeiro, which is already in a critical situation regarding the handling of cases of Covid-19², the Brazilian Network for the Inclusion of Persons with Disabilities - Rede-In, composed of several professional entities, councils, and associations, signed the manifesto entitled "All lives matter", addressed to the State Executive Branch because of the risk of illegal exclusion in the care of persons with disabilities in Intensive Care Units. The document presents a strong position against the establishment of a protocol that could harm the right of the disabled person to be served in case of need, demanding from the public authorities the recognition of the "equal value of human life, without any form of discrimination, and the indispensable to meet the specific needs of these people with equity" (REDE-IN, 2020, p. 3)

The CNS also recognized the vulnerability of persons with disabilities in the pandemic scenario, which motivated the elaboration of Recommendation nº 19, of April 6, 2020, and Recommendation nº 031, of April 30, 2020, both directed different public bodies and institutions. There is an understanding that the fight against the pandemic must be intersectoral, that is, in addition to health care, several areas must be articulated to enable social protection for persons with disabilities.

Resolution No. 19 recommends that the Ministry of Health, together with the Ministry of Citizenship, Justice and Public Security, and the Ministry of Women, Family and Human Rights, "present flows and alternatives to access to medicines and other items necessary to maintain the lives of persons with disabilities during the period of social isolation" (CNS, 2020a). The defense of health care in emergencies with equality,

² According to the Coronavirus Panel of the Ministry of Health, on May 27, 2020, the state of Rio de Janeiro had 42,398 confirmed cases and a record of 4,605 deaths.

in turn, is dealt with in the following Resolution, which condemns discriminatory attitudes and behaviors affirming principles of human dignity, equality, and acceptance of persons with disabilities as part of human diversity (CNS, 2020b).

In a similar sense, the National Council for the Rights of Persons with Disabilities (CONADE) was positioned, which, employing a note, emphasized the need for emergency measures to protect the Brazilian population, particularly those in situations of greater vulnerability or disadvantage, such as the segment of persons with disabilities.

CONADE's public note reiterates the guarantee of priority care already provided for in the LBI and presents a recommendation for including this public in priority care, especially in health care units (CONADE, 2020). Besides, CONADE communicated the urgency of including persons with disabilities in the risk group within the scope of COVID-19 to the Chamber of Deputies through the External Commission to monitor preventive health surveillance actions and possible consequences for Brazil regarding the confrontation of a pandemic caused by the coronavirus. This would allow all the treatment that is given to the elderly, people with chronic diseases, pregnant women and mothers of newborns to also be extended to persons with disabilities, recognizing the vulnerabilities to which this segment is exposed (SOUZA, 2020).

From the manifestations of councils and civil society entities analyzed here, another dimension of the right to life is identified, related to the guarantee of care actions for activities of daily living such as food, hygiene, and mobility, especially in the case of more severe disabilities. Such activities are historically and socially attributed to families and particularly to women (BRACCIALLI *et al*, 2012; MASUCHI, ROCHA, 2012).

Concerns about the illness of caregivers or confirmation of contagion from Covid-19 by family members of persons with disabilities were addressed in the notes analyzed in this article. CNS Resolution No. 16, for example, presented a recommendation to the Ministry of Health, together with others, to present alternatives of care for persons with disabilities, in case of illness of their caregivers. The manifesto of Rede-In, in turn, highlights the guarantee of reception of persons with disabilities by bodies of the Guarantee System for the Rights of Persons with Disabilities and the Unified Social Assistance System, especially tutelary councils, Social Assistance Reference Centers and Specialized Social Assistance Reference Centers, in cases when caregivers need to be hospitalized or placed in isolation.

In Brazil, in addition to the family, there has historically been the participation of civil society entities in the provision of assistance and social protection actions for

persons with disabilities (FIGUEIRA, 2008; LANNA JÚNIOR, 2010; MAIOR, 1997). The CONADE Note presents recommendations in this regard, by proposing the maintenance of partnerships between public agencies and these organizations aiming at the continuity of services, especially those related to long-term care, as well as support for social actions of these entities and the inclusion of persons with disabilities and their families in assistance and emergency programs.

From the analysis of the documents, it is possible to identify expressions of the horizontal understanding of the right to life, articulated to social assistance, work, and income policies, with emphasis on the removal of persons with disabilities from their work environments due to contamination risks, without loss of remuneration. The CNS, for example, recommended the Ministry of Economy to present a financial policy that is capable of offsetting possible impacts on families composed of persons with disabilities, and also ensuring that this group is able to leave work, as they are more vulnerable to any complications. Also, it suggested ensuring access to registration in the social assistance facilities and the release of the Continuous Payment Benefit during the period of social isolation. In response to these demands, Joint Ordinance 3 established rules for the anticipation of the BPC in the amount of R\$ 600.00 for up to three months, considering the enrollment in the Single Registry of the Federal Government and the Registry of Individuals, and the income criterion per capita.

Protection against violence and mistreatment of persons with disabilities, as well as the expansion of appropriate channels of denunciation, were recommended by the CNS to the Ministry of Women, Family, and Human Rights, recognizing that the social isolation scenario contributes to a greater occurrence such violations. A similar concern was pointed out by Rede-In, which recommended the adoption of measures to prevent abuse and violence in long-term care facilities for the elderly, shelters, home homes for children and adolescents, inclusive homes for young people and adults, among others; and also measures that prevent, inhibit and address cases of violence practiced by caregivers, family members or spouses against persons with disabilities, during the period of isolation at home.

The manifestos and notes analyzed in this article express the relevance of civil society entities that defend the rights of persons with disabilities to guide their needs in the context of a pandemic. In this sense, CONADE recommends the involvement of the Councils for the Defense of the Rights of Persons with Disabilities in all actions to be implemented in the three spheres of government (CONADE, 2020). At this point,

there is the statement of the motto “Nothing about us without us”, which marks the struggle of this segment for recognition since the 1980s.

Final considerations

The pandemic has made more explicit the social restrictions that have historically marked the lives of persons with disabilities. The difficulties of inclusion and accessibility have never ceased to exist in different areas of life for this population, but they seem to gain more worrying attributes in the face of the precarious confrontation of the pandemic by the public authorities in Brazil.

The preventive measures that should be taken seem to lose a place for the omission in actions for the right to life. It is a contradiction of serious consequences: failure to act for the benefit of the community brings harmful results that even demand the establishment of a protocol that aims to select who is entitled to a respirator in medical care, a measure that violates any protection of the right to live and could have been avoided by more effective and anticipated actions by the State. The same country that proposed to guarantee all the rights to the dignified life of the person with disabilities, including through the ratification of the CRPD before the international community, today is showing itself to be a State that violates essential rights to dignity.

The role of civil society becomes foremost in a context in which the State's priorities seem to be lost amid bureaucratic obstacles and political decisions that do not provide actions that guarantee essential rights for persons with disabilities. There is disrespect for the lives of those who should receive adequate protection for their needs, which becomes even more serious in atypical contexts, as experienced in the pandemic caused by the coronavirus.

Without pretending to exhaust the analytical debate on the recognition and guarantee of the right to life of persons with disabilities in the context of the pandemic, this article has presented some introductory notes. In the context of a pandemic, defending the right to life of persons with disabilities means that they cannot be neglected, whether in access to prevention information or treatment measures.

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RESUMO:

As reflexões apresentadas no presente artigo tratam da garantia do direito à vida a todos por parte do Estado brasileiro reconhecendo as especificidades das pessoas com deficiência no contexto de Covid-19. O percurso metodológico analisa manifestações e notas públicas de conselhos e entidades da sociedade civil de defesa de direitos das pessoas com deficiência frente às ameaças durante a pandemia. Observa-se que esse segmento se torna mais vulnerável à contaminação e às suas implicações. Destaca-se a mobilização da sociedade civil para defender a garantia do direito à vida e dignidade humana.

PALAVRAS-CHAVES: Vida; Direito à vida; Direitos humanos; Pessoa com deficiência; Covid-19.

contexto de Covid-19. La ruta metodológica analiza las declaraciones públicas de los consejos y entidades de la sociedad civil que defienden los derechos de las personas con discapacidad frente las amenazas de la epidemia. Se observa que este segmento se vuelve más vulnerable a la contaminación y sus implicaciones. Se destaca la movilización de la sociedad civil en la defensa de la garantía del derecho a una vida digna.

PALABRAS-CLAVES: Vida; Derecho a la vida; Derechos humanos; Persona con discapacidad; Covid-19.

RESUMEN:

Las reflexiones presentadas en este artículo tratan acerca de la garantía del derecho a la vida para todos por parte del Estado brasileño, reconociendo las especificidades de las personas con discapacidad en el