# On living in an ableist city: before, during and after the COVID-19 pandemic

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**Abstract** The images of cities before, during and after the COVID-19 pandemic represent a contemporary challenge. During this period, thinking about being a person, being there and living in an ableist city/society brings to light the loss of rights and the demands of population segments, particularly in the face of architectural, communicational, attitudinal, sensory and sociocultural barriers. To thematize about experiencing the different types of daily inaccessibility in the cities come into contact with and raise discussions about the ethical-aesthetic level of the existential territories of people with disabilities and mental suffering. To what extent do urban planners maintain concepts that support invisibility constructs, which reflect segregations generated by macropolitics? Would they be imagining the cities without thinking about the people who inhabit them? The present essay collaborates with the debate on the need for actions aimed at overcoming capacitism. Based on critical science theories and the concept of the health subject's right, the "topic landscape" is explored with a view to implementing accessible and inclusive public policies.

**Key words** Disability, Disabled persons, CO-VID-19, Normativity

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## Introduction

The analysis of being a person, being there, inhabiting places takes on dramatic contours when, in addition to the COVID-19 pandemic and its health implications, topics related to urban planning are overlapped.

Pandemic impacts were felt in different population segments, particularly among those who live in vulnerable territories, notably people with disabilities and/or psychological suffering.

Individually or collectively, these segments rise against different sociocultural barriers (from architectural to attitudinal ones), real obstacles to the expansion of existential territories, which according to Borges1 are characterized by their ethical-aesthetic dimensions in collective health.

In this sense, related to the COVID-19 pandemic, Medeiros and Rajs<sup>2</sup> emphasize:

[...] Reality has shown that the risks and catastrophic effects of the disease are disproportionately greater for vulnerable populations, especially those living in informal settlements, slums, urban plots, land occupations, as well as the homeless population [...] (p. 6)

What lessons about the lives of people with disabilities and/or mental suffering were assimilated in the context of the pandemic?

In this sense, reflecting on living in an ableist city/society - from 'ableism', a term according to which disability is seen as something to be "overcome or corrected" in contemporary society - includes both active and deliberate oppression as well as passive oppression, referring to the discussion of accessibility conditions of in slums and peripheral populations, rights without those the living becomes abstraction in existential territories, which Borges1 refers to as:

[...] every conceptual creation is historical, contextual and singular, always a singularity [...] the theory is the gateway to political engagement in a cognizable world, sharing existential territories that are not limited to the 'conceptual overflight' about the investigated reality[...] (p. 108).

The essay reflects on how living in ableist cities is hostile to the existence of people with disabilities, a segment that, according to the United Nations, represents approximately 15% of the world's population. If the UPIAS<sup>3</sup> – Union of the Physically Impaired Against Segregation (1975) considers the deficiency as a social oppression, what about the architecture of contemporary cities? The cities oppress people with disabilities and/or psychological distress, because the significant majority of sociocultural devices (such as museums, movie theaters, theaters, etc.) maintain a narrow view from a segregationist perspec-

When considering "disability" as a "social production", Kipen4 points out that "[...] the image of completeness, of the complete body, invents a deformed mirror of the incomplete, abnormal, inadequate body [...] the production of the normal body, [...]" (p. 129), ends up influencing the modern conception of cities and their social and cultural devices.

Thus, when cities/society are analyzed, there is a disclosure of the lack of public policies aimed at people, in which equity is present, guaranteeing respect for the insurgent rights<sup>5,6</sup> of the subjects who live in them. According to Santos<sup>5</sup>:

[...] never like today it was important not to waste ideas and practices of resistance. It just means that only by recognizing the real weaknesses of human rights is it possible to build on them, but also beyond them, strong ideas and practices of resistance. This reconstruction will allow human rights to become an instrument of fight, of resistance and alternative, albeit limited [...] (p. 104)

In this context, the issue of the rights of discriminated population segments (such as people with disabilities and/or psychological suffering) should not be separated from the analysis of globalization and the "human consequences", as proposed by Bauman<sup>7</sup>, considered the dimension of deterritorialization, in this essay based on an existential ethical-aesthetic basis in collective health.

Thus, it is understood that the reflections "on living in an ableist city: before, during and after the pandemic", the title of the essay, should not be separated from the precepts that underlie the condition of the subject of the health law.

# People with disabilities/psychic suffering and the impacts of structural ableism

On a daily basis, people with disabilities and/ or psychological suffering face barriers that make it impossible for them to exercise their fundamental rights. It is as if society told them "No".

The oppressive architecture in public spaces, the compassionate treatment or indifference are ableist forms that make it impossible for people with disabilities and/or psychological suffering to integrate society as subjects of rights.

However, from the perspective of human rights, contemporary studies on "disability" lead us to conclude that it is their "defective"/"abnormal" bodies that limit their existence<sup>8</sup>, taking away the responsibility of society and the societal structural ableism. According to the author, the ableist experiences modulate individuals and increase the dissonance in face of the normativity of bodies, causing fractures in the expectations of personal interactions, reaffirming differences in a non-silent way.

Ribeiro and Baptista<sup>9</sup>, in an instigating article, propose a reflection about the understanding of the "paradoxes of the production of difference in the present day"; they approach the "noises and silences of a body in the city", particularly those related to the principle of alterity of silenced or invisible bodies that circulate in "modern" cities. In the words of the authors, supported by Caiafa<sup>10</sup>:

[...] The cities generate a powerful space of exteriority that opposes both the interior of closed spaces and the interiority of the subject. The heterogeneity there activates, disperses identity focuses and familiar recurrences, thus introducing variation in subjective processes [...] (p. 92).

According to Adriana Dias<sup>11</sup> "ableism is the conception present in the social sphere that sees people with disabilities as non-equal, less able or not able to manage their own lives" (p.2), which, according to Campbell<sup>12</sup> (2001, 44), defines itself as: "a network of beliefs, processes and practices that produces a specific type of understanding of oneself and the body (body pattern), projecting a typical pattern of the species and, therefore, essentially and totally human". Disability for the ableist, according to Dias, "is a diminished state of the human being", or under the Foucauldian logic<sup>13</sup> of "talking" in which the condition of subject is reduced to an object under the magnifying glass of biopower, since words:

[...] that mean things are called noun names, like earth, sun. Those that signify the modes, marking at the same time the subject they are suitable for, are called adjectives, such as good, fair, round [...] Between the articulation of language and representation there is, however, a game [...] (Foucault 1995, p. 114)

This "game" of representations reserves a particular space for the language of deficit<sup>14</sup> which, continuously reified, inundates culture with ableist expressions. Foucault<sup>15</sup> in defense of society, highlights the perspective of the "insurrection of knowledge against the institution of power of scientific discourse" (p. 19).

Thus, the impasses arising from everyday inaccessibility, the naturalization of body normativity, resulting from the idealized view of the human being – reiterates the idea of isolation,

which, in this sense, is much prior to the pandemic –, constituting the "existential soup" of those who survive with disabilities and/or psychological suffering in oppressive urban environments.

In contrast to this segregationist posture, it is in the cities that equitable public policies arrive, or, at least, they should. Therefore, consistent with the essay ideas, it is postulated that the needs of people with disabilities/or psychological suffering cannot be denied based on ableist assumptions, which ignore the rights of health subjects. It is debatable that urban planning in cities is based on a biased look in which statistical percentages (for instance, people with disabilities) define the *modus operandi* that discriminates housing projects that are adequate to the specificities of subjects with health rights.

When clarifying the abovementioned concept, Vasconcellos and Oliveira<sup>16</sup> reaffirm that:

[...] the role of the citizen, far from being a mere performer of actions dictated by technicians and public authorities, is also that of a 'health subject', critical and co-responsible for the collective process of health construction [...] (p. 16).

Hence, the authors<sup>16</sup> emphasize that the expression 'health subject' deals with paradigmatic migration, a transformation from someone seen as a mere *object* of policies (health, work, housing) into someone else, an *active subject*, formulator and supervisor of their rights. (highlighted by the authors)

By superimposing the limits of the rights of the health subject relationship into beyond the health field, it is identified that the perspectives on being a person, being there, living in a city depend on individual and collective engagement of the subjects, in opposition to the ableism inherent of the human condition in social life.

Therefore, this essay calls for an overflight over the "landscape of cities", which will lead to the "thematic landscape", of the person with a disability or mental suffering, starting from theories of critical sciences and the concept of the health subject's right. The stimulus of thinking, via Homo Faber sennettiana17, establishes a kind of "tour" in which ableist cities do not result only from the academic production, but perhaps from a poetic and political-aesthetic "artivist" perspective. This "thematic flyover", however, can originate from artistic-cultural performances (installations in museums, festivals, popular songs, poetry) that oppose the ableist symbology, which subtly or not, spreads throughout culture when the language of the deficit<sup>18</sup> of biopower, reduce

subjects to objects of the body-normative narrative.

As an example of an anti-ableist perspective, the present essay uses a fragment of the poetry of Carmen Vallejo19, which exposes what people with disabilities experience:

[...] Mi cuerpo ME sirve a mí. Para sanarme. Y sanar con las mías. Algo para lo que la sociedad de fuera, esa que nos nombra discapacitadas nunca ha sido capaz ni ha servido de nada [...]

Thus, in addition to the anti-ableist confrontation of overcoming barriers in the productive model of society, we seek to affirm the locus of the existence of the singularity of the subject's right as an everyday political praxis.

When facing the erasure of the existential mark of different people in the societal process, it becomes crucial to deconstruct the idea of "incompleteness and abnormality" of bodies, and use the theories portrayed in the documentary "Crip Camp"20 which, as "mirrors" of reality, reveal that it is the ableist cities/society that are the incomplete ones.

# Faced with the pandemic necropolitics, how can we face setbacks in the field of human rights?

In the recent past, counter-hegemonic responses of an anti-asylum nature have been established. The suppression of funds for longterm hospitalization reoriented the care process, opposing social segregation, (re)integrating people outside the hospital environment. Psychosocial Care Centers (CAPS, Centros de Atenção Psicossocial) and therapeutic residences have appeared, including in the social corpus - civitas sennettiana<sup>17</sup> - people who have been historically excluded who have become part of the scenery and can be a person, be at and inhabit the city. Similarly, the text of the International Convention on the Rights of Persons with Disabilities<sup>21</sup> was approved by the General Assembly of the United Nations on December 13, 2006, being promulgated by Brazil on August 25, 2009, through Decree N. 6,949, and being implemented as a constitutional amendment. Another document considered a new civilization mark in societal relationships, based on the premise of the concept of a health rights' subject, as discussed before, is the Brazilian Law for the Inclusion of Persons with Disabilities<sup>22</sup> (LBI / Law N. 13,146, of 7/6/2015). The LBI is also known as the Statute of Persons with Disabilities, and its 4th article establishes that "every person with a disability has

the right to equal opportunities as the other people and will not suffer any kind of discrimination on account of their condition" (p. 22).

Gertner and Vasconcellos23, mention the rights of persons with disabilities preserved in these two documents, as in article 11 of the Convention that establishes that the member States "shall take all necessary measures to ensure the protection and safety of persons with disabilities who are at risk situations", including in humanitarian emergencies.

However, at the time this essay is being written and the Covid-19 pandemic is registered, anachronistic measures seek to reestablish political-ideological setbacks, such as Decree N. 10.502/2020, whose proposal seeks to reinstitute the National Policy for Special Education, resuming segregating practices that have proven to be ineffective and even unconstitutional. These practices reinstitute the logic of marginalization of people with psychological suffering and/ or people with disabilities, similar to the mental asylum character of sad memory in the history of Mental Health. It also violates the right of everyone to live in a plural and diverse society, without discrimination of any kind. Although the aforementioned decree is suspended awaiting judgment in the Supreme Court for Action of Unconstitutionality (ADI) 6590, the insistence of conservative forces of a segregationist nature remain and present themselves as a risk in a time when the necropolitics is exalted and practiced in these dark times of national politics.

Thus, this essay seeks to highlight, on the one hand, the critical-practical deconstruction of the model that reproduce practices with a mental asylum profile, as in the case of the insane hospital logic. Thus, by advancing Sennett's socio-anthropological understanding of the "flesh versus stone" relationship, addressed by Duarte<sup>17</sup>, the logic of the population's rights is reinstituted, based on the perspective of living according to ties of territorial bases of human existence. According to the author<sup>17</sup>:

[...] this process is constitutive of a democratic and plural society, insofar as it also aims to establish channels of sociability between different people; however, protecting the diversity within one's intimacy, without promoting the integration of differences, makes the first task innocuous [...] (p. 57-58)

Approaching the "itinerary of Richard Sennett's social criticism", Duarte<sup>17</sup> also emphasizes that the aforementioned dynamic is considered by Sennett as part of the "tyrannies of intimacy". In Duarte's words, this type of tyranny:

[...] refers to the act of disregarding the existence and needs of the other – a kind of 'reciprocal possessive individualism', which ends up harming the conditions for cooperation and social interaction. This gives rise to an ideology of intimacy: the social evils would be derived from impersonality, alienation and coldness – the solution would involve rescuing the privacy/intimacy. But it is in it that the isolation of the subject is cosubstantiated [...] (p. 58).

According to Duarte, when analyzing the modern *polis*, Sennett states that the city – post-French revolution – aspired to "create a space of freedom in which coming and going did not find any barriers, but in practice ended up generating empty or transiting urban spaces, the non-places [...]" (p. 58).

And concludes17:

[...] without the civitas, it loses its instance of social articulation and becomes an amorphous conjunction of spaces and bodies that do not communicate [...] Sennett will verify that life in large cities 'socializes space', but promotes individualism and it silences bodily practices, with its emphasis on mobility [...] (p. 59).

## People as texts & cities as a social body

This essay uses Gergen<sup>24</sup> when using the metaphor of people as "texts", which directs the argumentative line that "various texts" inhabit a permanent "reading/rereading" of Each Other. Borrowing from this Gergenian metaphor, it is assumed that the "cities" represent a space in which texts can be found included in "books", which, strictly speaking, must constitute the large "library" collection of the social body. One wonders, therefore, who in the "social body", a priori, exercises the power to censor the presence of people as texts (with disabilities and/or psychological suffering) as evidence of differentiated existential territories? One also wonders, what "editorial values" have governed the "intertextual" relationships established in society? How does the actual knowledge of people with disabilities or psychological suffering contribute to the transformation of "cities/society" with an ableist profile?

It is, therefore, impossible to deny that in the III Millennium the invisibility character of "people as texts" remains, sometimes stigmatized as "disabled", "crazy", "autistic", aprioristically existentially censored in cities and in society in general. This process results from the diffusion in the culture of terminologies found in the DSM

V, enclosing them in essentialist deficit taxonomies14,18,,25,26, many of which provide feedback to the currently used ableist values. A large part of this "biographical censorship" results from the performance of the medical-academic-industrial complex<sup>27, 28</sup> (MAIC), by transforming subjects of rights into objects of discourse, making culture progressively ill. In this sense, the ethical-aesthetic existential territories of people labeled as "mental patients", "disabled", have their social and cultural intertextuality made invisible. Blikstein<sup>29</sup>, tacitly demonstrated that positive or negative valences are found in the "semantic corridors" of the manufactured language, which determine symbolic marks in the existence of people described by social constructs of the deficit language.

Therefore, it is essential that "people as texts" seek to materialize insurgent ways to oppose this type of epistemic injustice, transforming the "non-place" attributed by the bio-ableist power into a "place of political (re)existence", enabling the defense of their rights, such as the perspective of the diversity of the human condition, which Lukács<sup>30</sup> refers to as the basis of the ontology of the social being.

Starting from an anarcheological stance<sup>31</sup>, anti-ableist poetry and manifestos should result, which should be "read from the inside out", as part of the "collection" where everyone is a person, is there and inhabits cities, faithfully translating the pluriversified portrait of society, breaking the body normativity – imposed from the outside, which censors "texts considered to be imperfect".

Biographical narratives of the self, as "people as texts" make up the social "corpus", which in the form of insurgency against the invisibility, reaffirms the diversity inherent to the human condition

To that, Avelino<sup>31</sup>, based on Foucault's political thought, calls the production of subjectivity. Therefore, the "mark of destiny" is abandoned and the demarcation of a new existential ethical-aesthetic territory in Public Health is assumed.

This essay questions the "modus operandi" of modern society formulated from the body normative logic where "people are considered as normal/perfect". Thus, when faced with a society with a segregationist/ableist profile, it is understood that the latter models political devices, denying ethical-aesthetic existential territories of people and their singularities. To deny the existence of people with singularities gives way to "si-

lenced noises", as Ribeiro and Baptista9 point out.

Just like Judith Heumann<sup>20,32</sup>, the essay questions societal attitudinal barriers that stigmatize, making the city (full of "books" to be read) a place for "ideally perfect bodies". In the broken city, "censored texts" continue to live excluded in "ghettos", without access to spaces that do not respect their singularities.

# The first person singular & the first person plural in the societal body

Weakened amidst the pandemic, the ontology of the social being<sup>30</sup> ends up restricting intersubjective exchanges and belonging to the social body, displacing territorial existences from the first person plural (WE) to the first person singular (I), which in large part, reinforces Sennett's "tyranny of individuality", hindering "artivism" and collective insurgency, so necessary for people with disabilities and/or mental suffering.

But that does not happen in isolation, or outside a broader political context.

It should be noted that socio-historical invisibility; the political-assistance gaps; and, the loss of rights, result from the advances of the (ultra) neoliberalism in Latin America<sup>33</sup>. In this context, disability is synonymous with social oppression and body normativity, as much as psychological suffering reiterates the pathologization of everyday life, segregating and excluding people who differ from the norm. From a practical point of view, a society whose neoliberal structures are based on individualism and meritocracy, leaves no room for any collective posture other than that of insurgency, opposing the concessions of a charitable-religious profile. In the context of a conservative profile, Michel Foucault's<sup>31</sup> political thought redirects the classic individualist attitude to the positioning of a collectivist profile of organized social movements. What alternative is offered other than militancy? The collective must impose its banners of struggle over living in society, where being a person, being there and inhabiting a city must transcend the (geo)physical space, as postulated by Bachelard.

The absence of public policies with an anti-ableist attitude points to a broader thematic set in the intersectional perspective and the microphysics of power<sup>34</sup>. Thus, in the civitas so desired by Sennett<sup>17</sup>, each social being counts as part of citizenship, assuming that the incomplete and imperfect city contributes to the observation of political gaps, particularly for those who are marked by differences ("disability", "madness"), in a society idealized by the perfection of secular inspiration.

We corroborate the political thinking of Saul Newman<sup>35</sup> by admitting that "if power is everywhere, if it is coextensive with social relations, if it is present in everyday interactions, what space is possible for freedom?" (p. 321). The response to the questioning is associated to the idea that power and freedom exist "in a relationship of mutual incitement and provocation, in which each is opposed to the other, but also in which each is a condition for the actual existence of the other" (p. 322).

In other words, it resides on the level of subjectivities, identifying forms of resistance, contesting the power that reduces subjects of rights to objects of servitude of (ultra)neoliberal practices. The liberation outlined here begins with a fierce opposition to the language of deficit - which is very similar to a new "eugenic nightmare" - followed by critical thinking. In order for us not to resume the "war of races" denounced by Foucault<sup>34</sup>, it is essential what Newman understands by the attitude of the subject of rights, which affirms the primacy of freedom, refusal of obedience and oppression:

[...] the subject attributes to themselves the right to question the truth with their effects of power and to question the power over their discourses of truth. Criticism will be the art of voluntary inservitude, of reflected insubordination [...] (emphasized by the author, p. 329)

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## **Final considerations**

The idea of being a person, being there, "inhabiting the right to the city", is introduced in these considerations as "verbs", which illuminate the thematic, giving it relevance, more particularly when the human condition is exposed to a health crisis of unimaginable proportions.

This essay, essayistically organized, challenges the ableism crossed by elements that continuously structure the ways of seeing and hiding people's bodies and their ethical-aesthetic-political existential territories.

Only the sociocultural decolonization enables the emergence of new existential territories for people, attributing symbolic meanings to the praxis of being a person, being there and inhabiting a society in the process of (co)construction,

in which subjects of rights reaffirm their (re)existence.

In this sense, the present essay opted for collectivization by reflecting that being a person, being there and inhabiting a city takes place by occupying insufficiently accessible buildings and streets; blocking access roads through the "cripcamp" route, circulating noisy bodies in the downtown of cities as part of an "artivist installation" — of wheelchairs, prostheses, orthotics — where the sign of freedom from oppression manifests itself. If they only see us in an "idealized" way, from now on, they will come to see "political obstacles" made of flesh and blood, as (re)existences in which health right subjects will fight for the effectiveness of anti-ableist public policies. Therefore, the dimensions of accessibility and

inclusion are not concessions from the State, but sometimes manifest themselves as matters of principle, which are not given up in the form of fight and (re)existence.

In other words, the excerpt from Carmen Callejo's anti-ableist poetry "my body serves me", in a free translation, is a manifesto for cities/society to be thought of by everyone and for all the people who live in them. Therefore, thinking about being a person, being there and inhabiting is to recognize the act of rebellion against (bio) ableist rules, which regulate urban planning, usually aimed at "perfect bodies" that fit the *modus faciendi* of "modern" architecture and engineering.

It is said that the future "brings surprises"; it remains to be seen what kind of "post-pandemic" society will organize itself, ableist or anti-ableist?

## **Collaborations**

AC Amorim and SRCB Gertner conceived the original idea for the article and supervised the writing of the manuscript. LS Costa and AP Feminella, co-authors, collaborated, co-wrote, reviewed, and commented on all sections of the manuscript.

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