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Care for disabled people with complex dependency: a matter of justice

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Abstract: The purpose of this text is to problematize care for disabled people who experience complex dependence and to defend care as a matter of justice. To do so, we establish a dialogue between disability studies and a political-feminist ethics of care. In the first section we approach the theme of care from a political-feminist perspective. We then discuss how ableism and familism, in line with neoliberal policies, obstruct access to care, which is accentuated during health emergencies such as the Covid-19 pandemic. Finally, based on the understanding that care provided by the state is a matter of justice for people with disabilities, we present some ethical-political principles that help qualify the debate on this subject and foster the construction of emancipatory social policies.

Keywords: Care; Disabled People; Complex Dependency; Ableism; Justice.

Cuidado na dependência complexa de pessoas com deficiência: uma questão de justiça

Resumo: O objetivo deste texto é problematizar o cuidado de pessoas com deficiência que experienciam a dependência complexa e defendê-lo como uma questão de justiça. Para tanto, estabelecemos um diálogo entre os estudos da deficiência e uma ética político-feminista do cuidado. Na primeira seção, apresentamos o cuidado a partir da perspectiva político-feminista. Em seguida, apontamos como o capacitismo e o familismo, em consonância com as políticas neoliberais, obstaculizam o acesso ao cuidado, algo acentuado em épocas de emergência no campo da saúde, como durante a pandemia de Covid-19. Por fim, com base no entendimento de que o cuidado público é uma questão de justiça para pessoas com deficiência, apresentamos alguns pressupostos ético-políticos que contribuem para qualificar o debate sobre o tema e fomentar a construção de políticas sociais emancipatórias.

Palavras-chave: cuidado; pessoas com deficiência; dependência complexa; capacitismo; justiça.

El cuidado en la dependencia compleja de las personas con discapacidad: una cuestión de justicia

Resumen: El propósito de este texto es problematizar el cuidado de las personas con discapacidad que experimentan la dependencia compleja y defender el cuidado como una cuestión de justicia. Para ello, establecimos un diálogo entre los estudios de la discapacidad y una ética político-feminista del cuidado. En la primera sección, presentamos el cuidado desde una perspectiva político-feminista. A continuación, señalamos cómo el capacitismo y el familismo, en línea con las políticas neoliberales, dificultan el acceso a los cuidados, algo acentuado en tiempos de emergencia en el ámbito de la salud, como durante la pandemia del Covid-19. Finalmente, a partir del entendimiento de que el cuidado público es un asunto de justicia para las personas con discapacidad, presentamos algunos supuestos ético-políticos que contribuyen a cualificar el debate sobre el tema y favorecen la construcción de políticas sociales emancipatorias.

Palabras clave: cuidado; personas con discapacidad; dependencia compleja; capacitismo; justicia.

Introduction

Caring activities are essential to the survival and maintenance of a wide variety of life forms, and among humans involve the lives of individuals and their societies. Given human fragility and vulnerability, it is not possible to survive the first years of life without daily and constant care, which must be maintained for more than a decade for an individual to become an adult. After this period, the need for care does not disappear, given that fragility and vulnerability are unescapable conditions of corporal and mortal beings. In addition, individual and social life are marked by periods in which care must be intensified, given the experience of illness — physical or emotional — and aging. As indicated by Virginia Held (2007, p. 173), humanity would not survive without caring relations.

After nearly four decades of feminist research about this theme,¹ it can be affirmed that care has at least five objectives: to respond to the basic needs of an individual, group, or ecosystem; to assist individuals, groups and ecosystems to survive; to avoid or alleviate unnecessary or undesired pain and suffering; to promote the development of the abilities of individuals; and to assist humans to live in society (Carol GILLIGAN, 1982; Sara RUDDICK, 1989; Joan TRONTO, 1993; Eva KITTAI, 1999; Daniel ENGSTER, 2007).² There is also a consensus that different individuals manifest their needs in different ways and that these objectives are only attained in a complex and vast network of relationships.

Feminist researchers who have been producing knowledge in the field of care, such as Kittay (1999) and Tronto (1993; 2013), reveal that understandings about this category are not neutral. There are political implications to the production of knowledge about care, in the construction and implementation of social policies for providing it (or not) and in how the collectivity organizes to exercise it. In this study, corroborating the research of Helena Fietz and Anahí Mello (2018), we understand that care can be a powerful analytical category for the field of disability. In the general imaginary, disabled people are directly associated to care and are intensely dependent on it. It is therefore necessary to provoke a broad discussion about the ways that care is instrumentalized and to serve whom.

Every society has a group of people who live with complex dependency, which, in this article, in contrast with the definition proposed by Stacy Simpican³ (2015), we conceptualize as the type of dependency experienced by people who, because they have a high degree of impediments — physical, sensorial, intellectual, psychosocial or multiple — require help and or support for most activities in which they want or need to participate. Dependency is commonly understood to be related to needs considered elementary (eating, hygiene and care for the maintenance of living bodies) and circumscribed to the private realm (in people's homes or at most in healthcare services that they need to stay alive). However, based on a feminist-political perspective, we understand that complex dependency must be incorporated in the public realm, to guarantee the social participation, in their particular form, of people who require considerable help and support.

Making complex dependency visible is essential to the construction of social policies aimed at effectuating rights already guaranteed by Brazilian law⁴ to all disabled people, including those who will need greater support to access these rights. We believe that considering complex dependency as an analytical category contributes to the construction of knowledge and practices aimed at curbing processes that increase the precariousness of life, which can be caused by neglecting the needs of people, sexual/domestic violence, compulsory institutionalization, sterilization, and other mechanisms of oppression.

Kittay, referring to the care of disabled people, in an interview with Marivete Gesser and Fietz (2021), emphasized the need to break from perspectives that locate it as a family issue, to be resolved in the private realm. Kittay proposes that care be understood as work that must be remunerated and as a right, a question of justice for disabled people. In addition, she argues that, for everyone to have access to good care, it is necessary that it be valued and offered by the state. However, despite the countless advances obtained in Brazil from a legal perspective since the approval of the Convention on the Rights of Persons with Disabilities (CRPD) (Decreto Legislativo nº 186, de 09 de julho de 2008) and the Brazilian Law for Inclusion of Disabled Persons

¹ The book *Uma voz diferente*, [A Different Voice] by Gilligan (1982), is considered an initial contribution to research in this field in Brazil.

² The issue of care and interdependence between non-human animals and humans with nature is not present in these authors, whose work we use to point to the objectives of care. Nevertheless, this is a logical and possible consequence that we defend, although it is not explored in this article.

³ Simpican (2015) conceptualizes the situation of complex dependency as that which involves people with a high degree of dependency and vulnerability that also manifest aggression, which complicates even more the relations of care in which they are involved, given that violence is something present and recurrent.

⁴ The Convention on the Rights of Persons with Disabilities – CDPD (Decreto Legislativo nº 186, de 09 de julho de 2008) and the Brazilian law for the Inclusion of People with Disabilities – LBI (Lei nº 13.146, de 06 de julho de 2015) are two important laws that guarantee rights for people with disabilities.

– LBI (Lei nº 13.146, de 06 de julho de 2015), the right to a caregiver for disabled people in a situation of complex dependency has still not been established.

This article problematizes the care of disabled people who experience complex dependency, defending it as a question of justice. We begin from the presumption that ableism and familism are systems that sustain neoliberal policies, which keep care in the private realm as an eminently female activity, reaffirming historic gender inequalities.

Ableism is conceptualized by Fiona Campbell (2001, p. 44) as “a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human”. Mello (2016) emphasizes that ableism creates an hierarchy of people as a function of the suitability of their bodies to corporeal normativity, treating them, in general, as being incapable of conducting ordinary activities, such as working, learning something, providing care, loving, feeling desire, and being desired, or having sexual relations.

Familism, in turn, is understood as a type of welfare system being placed in operation in a patriarchal capitalist context. In it, the family is designated as being principally responsible for the well-being of its members and women assume a disproportional burden of caring activities (Luana PASSOS; Celia KERTENETSKI; Danielle CARUSI MACHADO, 2021). Wederson Santos (2017; 2014) and Gøsta Esping-Andersen (1990) indicate that in this system, the state's presence as an agent responsible for caring for the population is quite reduced, given that families are the main promoters of care and social protection, assuming functions that should be provided by the state through public policies.

Ableism and familism favor neoliberal policies, because they corroborate the practice of this system in subjecting the demands of individuals to the market and family. As Robert McRuer (2012) affirms, neoliberalism is the dominant economic and cultural system of our time. Its main characteristic is the premise that the market can most efficiently and effectively resolve all problems existing in society. This system shifts the previously public functions (that were the state's responsibility) to the private sphere. Thus, “because neoliberalism depends on private solutions to all problems, ‘the family’ takes on an increasingly important role as the provider of goods and services like caring labor for those who are young or elderly” (McRuer, 2011-2012).

The limitation of care to the family, indicated by McRuer (2012) due to neoliberal policies, increases the vulnerability of disabled people who live a complex dependency in situations like the Covid-19 pandemic, given that many people who exercise care are from risk groups and have a greater probability of dying if they are contaminated. For disabled people who depend on their families to have access to care, and are not able to seek out this service in the market, the pandemic can produce considerable anxiety. In a study conducted by Karla Luiz (2020, unpublished) to identify the experience of complex dependency of women with disabilities, one of the participants described the anguish she felt from the fear of losing her care providers, who are her parents who belong to a risk group:

I became quite anguished thinking [of the loss], because they are also getting old and now, with the pandemic, the anxiety that I felt about my contamination and theirs – that is, more theirs than mine. Because I believe that thinking of my death is not something that disturbs me but thinking of their death makes me very upset. Because I think: ‘everything I do today I only do because everything is organized by them, right, it’s all organized, shared by them and all’. If they die, or if one of them [dies], then the structure won’t be the same (Lígia, oral communication, July, 2020).

This statement demonstrates how much the pandemic and its consequences amplify and intensify the barriers and “processes of exclusion that disabled people already experienced” (Fábio CRISTO; Renan SOARES JR.; LUIZ; Andrea NASCIMENTO, 2020, p. 6). That is, beyond the fear of losing their caregivers for common reasons, the pandemic brought the imminent risk of illness and death from the coronavirus. This new possibility of loss reveals the fragility of the situation of disabled people who have complex dependency, not because of the disability itself, but because of the lack of a public policy for care that can meet the needs these people have for support.

The understanding of disability as an individual and or family problem legitimates familist care policies. These policies imply a series of inequalities and injustices — of gender, class, ethnicity, and race. In this article we want to focus on the inequality and injustice that affect disabled people who experience complex dependency in access to care. In contrast to ableism, familism and other oppressive systems that impede access to the rights of disabled people, especially those marked by multiple intersections, we propose the incorporation of the principles of *Disability Justice* that in the portuguese version of this article we call *Defiça Justice (Justiça Defiça)*, in keeping with the translation proposed by Mello and Fietz (MELLO et al., 2021).⁵ This field will be placed in context in the following section of this article.

⁵ Since there is no literal translation into Portuguese of Disability Justice that accounts for the power of this theoretical and activist perspective, we have decided to translate it, for a Portuguese version, as *Justiça Defiça* (Defiça Justice).

Given the issues raised until here, the first section of this article presents the theme of care from a feminist perspective and indicates how it was feminized and privatized, at the same time that a new ideal of masculinity became adopted in modernity: that of the independent and salaried man. This ideal serves a capitalist system, and reinforces ableism, gender inequalities and familism as state policies. The two following sections discuss familism and ableism as practices that intensify inequalities and impede the struggle by disabled people for care. Finally, public care, supported by the state, is defended based on dialog with Disability Justice, which is a theory with political strength whose objective is to produce fissures in the ableism that is broadly present in the construction of social spaces and in the establishment of forms of relating with disability.

Care from a political-feminist perspective

Two facts stand out, initially, for those who study the topic of care: that caring activities are exercised mostly by women and that these activities are poorly valued or go “noticed” by most people. For many decades, these two facts have been associated to each other by female researchers and feminist activists, and their causes linked to ethical and political issues (RUDDICK, 1989; TRONTO, 1993; 2013; KITTAY, 1999; Ilze ZIRBEL, 2016).

Our contemporary societies are the result of long trajectories and social arrangements marked by the interplay of interests and conflicts among various and differing groups of people. Each one of us, however, begins their journey in life in a total state of fragility and dependence, receiving from the family circle not only the material care needed to preserve their life, but also indications about how society functions and the operating rules. We are surrounded by various caring activities, without truly recognizing them, and do not even have linguistic tools to elaborate our thoughts about what is happening.

Women throughout the world thus bear most of the responsibility for caring for themselves, their children, and family members with disabilities, the bed-ridden, elderly and all the adult men in their family. In many cases, it is expected that women will not develop personal plans or that they will leave them aside to exercise unlimited care for their family members, or even, of other social groups, as is the case of black or immigrant women. The idea of self-sacrifice to care for others accompanies the expectations linked to women (GILLIGAN, 1982), who are thought of essentially as care providers, as mothers and wives, with this being the fate imagined for the large majority of girls, especially those of the lower classes.

In parallel to the women care-giver model, we confront another model, aimed at the universe described as male: that of the independent or autonomous man. He operates in an essentially individualistic and self-interested way. He appears not to have significant needs or dependencies, is described as highly qualified — rationally and physically — and is not expected to assume activities related to caring for someone or even for himself (after all, one or a few women close to him will do this in his place). His fate is freedom and decision-making, even if this is a quite abstract ideal that is distant from the concrete reality of most real men.

By observing these two broad models of gender,⁶ we perceive that one of them, the female, is dedicated to care activities — and the maintenance of life of countless individuals and of society itself, in quite concrete, and necessary daily actions. The other model, considered male, is focused on an individualist posture, on the “world of ideas” and the “administration” of the family and society. Apparently, this is a type of social “division of labor” by gender or sex. However, there are countless issues of power and injustice involved in this division. For more than a century female researchers and feminist activists dedicated to considering the phenomenon of oppression and subordination of women in our societies have pointed to the relationship between this phenomenon and care activities (Nancy FOLBRE, 1991; Evelyn NAKANO GLENN, 1992; Silvia FEDERICI, 2012; Nancy FRASER; Rahel JAEGLI, 2020).

The model of the independent man is a type of fiction that hides not only all of the inevitable dependencies of this man (for food, shelter, affection, public policies, social institutions...) but the fact that he is dependent on caring activities undertaken by countless women and the fact that they do not receive the same type of support from the men with whom they share life in common. For many feminist theorists of care, the independent man is nothing but a myth or ruse of theories (TRONTO, 1993; Martha FINEMAN, 2004). Moreover, as Naïma Hamrouni observed (2021, p. 82), the idea of independence “is the reified product of a relation of power, a social status”, utilized

This expression was proposed, previously, by Anahi Mello and Helena Fietz (MELLO et al., 2021) at roundtable 04, of the VII ENADIR – Encontro Nacional de Antropologia do Direito [National Encounter of the Anthropology of Law]. Although Defiça is not formally part of Portuguese vocabulary, we believe that the use of this term can come to be expanded and adjusted to Brazilian reality. In addition, the option for the term “defiça” is in keeping with the self-identification of disabled people as “ativistas defiças” [disabled activists], as is occurring in Brazil. Our analyses indicate that this form of identification is a strategy for questioning the ideal of the universal subject and the way that spaces, times and forms of relating are constructed, as well as strengthening the activism of the disabled in Brazil.

⁶ Various other models are also part of our social realities. We choose to point only to these two, and quite briefly, because we understand that they continue to be a type of central matrix from which the others derive in a certain manner.

by those who receive services of care, it denies that they benefit from them and denies their responsibilities to provide them in exchange. This all takes place in a social and institutional context that supports this practice.

The fiction-myth of the independent man has been incorporated to moral and political theories, presented as an ideal for all and any person. In an article that traces the genealogy of the concept of dependence, Fraser and Linda Gordon (1994) indicate that it was during the expansion of capitalism that the idea of independence came to be associated to men, and in particular, those who receive salaries. The word hid and consolidated the process of domination by obscuring the new forms of dependence of the working class — on employment and the capitalist market — beyond the unescapable dependencies — on the activities of care provided by women and servants, in the realm of private life. The new system also made caring activities non-remunerated, something invisible and devalued, given that they confined them to the private-domestic space, and stigmatized the economic dependence of those who did not participate in the capitalist labor relations.

The devaluation and the invisibility of caring activities allowed the benefits and privileges produced to be understood as the results of some type of merit or skill specific to individuals and not the fruit of the dominant social structure and organization. Thus, both care and its agents are devalued to the point that these activities appear to be unnecessary or the result of the affection of women for their children, siblings, and husbands.

Narratives about care naturalize it and attribute it to women who, in turn were led to care for all the members of their family in the domestic realm (ZIRBEL, 2020). A set of inequalities and problems stem from this fact: women provide many more care services than they receive; men can dedicate themselves to other activities (remunerated ones for example) with much more facility; society loses a large portion of potential care providers (adult men); care is not understood as a public responsibility that should be incorporated to collective-public policies and concerns; thus, disabled people, children and the elderly receive care limited to the domestic realm and do not participate in countless collective activities – including decision-making and political activities; this is accentuated in the case of people with complex disabilities.

There are many interlinking issues in the web of social inequalities resulting from unequal and unjust organization of caring activities, including racial issues and ableism. A number of our institutions were historically constituted by the intersection of systems such as sexism, racism, colonialism, imperialism, ableism, and capitalism, as increasingly denounced by female researchers and feminist activists (Heleieth SAFFIOTI, 2015; Danièle KERGOAT, 2010; FRASER; JAEGGI, 2020). It is clearly perceived that patriarchal-capitalist societies are organized to provide, in the private and domestic realm, all types of care to so-called “independents” and maintain the operations of a political-economic system that gives privilege to the profits of a small group of men, who have the initial benefits of class, sex, color and physical-mental characteristics. In these societies, the practices of exclusion steer in various degrees those people whose bodies and minds differ from the model performed by this small group of men.

Injustice predominates largely in relation to the responsibilities and privileges related to care. Not only do men benefit from the sexual division of domestic work, but while men with political and economic power continue to regulate state actions, which prevents practices that are more equitable be established and that care be assumed as something public, to be considered and organized in favor of the entire population and produce less damage to nature and ecosystems on which we depend individually and collectively.

From a feminist perspective, a social and political reorganization is necessary to subvert the relations of care that are imposed, and various concepts and narratives that support it. In it, independent subjects give way to vulnerable and interdependent⁷ subjects (ZIRBEL, 2016) who understand that they are part of a world and society that is equally vulnerable and interdependent. Care is no longer invisible and gains a central space, not only in the field of ethics, but in politics. Without relations of care there is no self or society. Our identity, knowledge, motivations, possibilities, and affections are the result of all the relations woven throughout life, within and beyond the family, in a collective manner.

This does not only involve conducting politics differently, but constructing another form of politics, based on real, concrete lives and bodies and in opposition to a levelling universalism based on an idealized human model. We defend a policy founded on feminist, antiracist, anticapitalist and anti-ableist principles, with a central premise that no body or mind should be left behind, as has been defended by militants of Disability Justice (SINS INVALID, 2019). This implies using values and practices of care to guide the architecture of public spaces and institutions, institutional rules and laws, the world of domestic and non-domestic work, and the ways that people relate with one another. Care for all is a premise of justice.

⁷ In particular chapter 4.

Many challenges are currently faced along the path towards this alternative policy model. Identifying problems, provoking discussions, and clarifying concepts and ideas are necessary steps on this path. Thus, it is necessary to understand how the multiple forms of oppression imposed and interconnected by the current system function. Fortunately, there are increasing discussions in Brazil about sexism, racism, and homophobia, as well as studies about economic inequalities. However, there are still only a few that address the problem of familism and ableism which, based on our initial analyses, work together to delegitimize the rights of disabled people to decent, remunerated care, provided by the state, in keeping with the struggles of disabled people, so that disability and complex dependency are no longer an individual problem to be addressed in the private realm and come to be a question of justice and rights.

Familism

As briefly highlighted in the introduction to this article, familism is a system that places the main responsibility for the care and wellbeing of its members on the family. Thus, due to the juxtaposition of familism with the role of private practices of charity and philanthropy that have been present throughout the history of Brazil, the state has had a quite reduced participation in the provision of facilities and services for care and social protection in general (SANTOS, 2017). Santos also emphasizes that the role of the state, in relation to social security, decreases as the presence of the family increases. That is, there is only public intervention if the family is not able to assume responsibility for protection and care of its members. For some authors, this is not only a Brazilian reality, but is found in many Latin American societies (Guillermo SUNKEL, 2006).

Ponderation and analysis about familism is essential so that we can understand the impact that public policies have, "reinforcing degrees of oppression and inequality" by delegating to families an attribution that should belong to the state, that is, social protection. This system deepens inequalities between families and within families. This is because families with greater purchasing power are more able to contract private services to provide care. Meanwhile, in poor or racialized families, and with members with disabilities, the familist system overburdens mothers who, due to historic gender inequalities, wind up being those mainly responsible for caring for children, the elderly and people with disabilities.

Familism is strongly present in Brazilian public policies because there was a focus on the family at the time the Constitution was drafted. That is, the debate about social assistance was linked to agendas related to the family because of a historic proximity between social security and certain groups (children, the elderly and disabled people) and the family institution. Historically, Brazil has organized the social protection of subjects as charitable practices. According to Santos (2017), familism is a measure that restricts access to public policies and thus to the opportunity for emancipation.

Familism and ableism have common consequences: they prevent disabled people from being conceived as subjects with rights, given that they are seen as mere receivers of the benevolence and charity of other people — in this case, their families. We can even affirm that ableism and capitalism guide policies for disabled people who require long-term care, by positioning disabled people as inferior to others and delegitimizing their struggles for access to caretakers. This access is essential to guarantee participation in collective life.

Given that the form of organization of care services implies a neoliberal social reproduction and that there is a crisis of care being established by the social transformation of the role of women and the increased life expectancy of the population (those with and without disabilities), debate about care services is urgently necessary to construct policies that guarantee the dignity of citizens who require and or provide it (PASSOS; Dyego GUEDES, 2018).

The challenge presented is immense: how to dismantle public policies for care based on a familist perspective and support emancipatory policies in a society with ableist and capitalist operations? The premises that no one can be left behind (SINS INVALID, 2019) and that we must protect corporalities that McRuer (2006) denominated as multiple and alternative,⁸ are essential to generating a viable response that can lead to "defamilization".

Thus, we propose two possibilities: that the state offer public care services that guarantee the precepts of the documents that guide the rights of disabled people in Brazil (the CDPD and LBI) and that the state accept responsibility for financially subsidizing care services by means of monetary payments to people who need care, so that they can pay for care providers of their choice (even if these providers are family members). It is necessary to emphasize that the entire practice of care should consider how a person prefers to be cared for, that is, to the degree possible, people who receive care should be protagonists in the entire administration of their own care and their life (LUIZ; Thaís SILVEIRA, 2020).

⁸ McRuer (2006) used the expression multiple and alternative corporealities to denominate those bodies that differ from the standard of compulsory capacity required by neoliberalism.

The omission and negligence of the state are anchored in the familist perspective and it is necessary to break with it to overcome the inequalities and injustices that disabled people must live with, especially those with complex dependency. To do so, however, it is necessary to confront the ableism that is widely disseminated in society and its institutions. Familism and ableism act in conjunction in states strongly marked by neoliberal policies and corroborate towards the maintenance of care with a focus on the private realm.

Ableism and the delegitimization of the struggle for care

In this section we will first provide a brief characterization of ableism. We will then show how ableism, articulated to familist policies that are strongly present in Brazil, corroborate to delegitimize the struggle of disabled people for access to state provided care. Both ableism and familism contribute to maintaining disability as an issue in the private realm, an individual problem and at most, one pertaining to the family.

Campbell (2009) corroborated our argument that ableism delegitimizes the struggle for access to public care services. She defends that from an ableist perspective disability is an inherently negative category, something that should be “improved”, cured or even eliminated. This understanding reinforces the view that disability is a problem of the individual, in contrast to theoretical perspectives in studies of disability that highlight the political character of this category and call for the elimination of barriers and relations of dependency and interdependency so that

disabled people have the right to develop and participate in society with agency.⁹ Ableism produces framings that pathologize those people who deviate from this standard of the body, whether because they are distant from the ideal of ability or do not meet what Rosemarie Garland-Thomson (2002) called a policy of appearance that intersections with the medicalization of subjugated bodies, in an effort to normalize them.

Inspired by the studies of whiteness that have been developed by Lia Vainer Schucman (2020), we have considered that, like whiteness, ability is also a privilege. We defend this argument based on analyses about the Brazilian context. In it, we can observe that, although we have one of the world's most advanced legal frameworks regarding the rights of disabled people (Izabel MAIOR, 2017), there are still countless barriers that impede their access to education, labor, healthcare services and leisure. Due to these barriers, to perform ability is configured as a privilege.

Ableism is based on the understanding of disability under a medical model that sees it as an individual problem in the private realm, and which stems from a pathology of an organic origin, which must be avoided and that, when this is not possible, requires actions focused on cure and charity. Based on an ableist perspective, disabled people and their families must “overcome disability” through a search for medical resources and accessibility so that disabled people can have access to activities such as work, study, and community life.

Moreover, ableism strengthens neoliberal policies, because by circumscribing disability as an individual problem, due to the deviation from what is considered to be typical for the species, it delegitimizes the struggle by disabled people and their families for services and accessible spaces prepared to shelter multiple corporalities, which removes the state's obligation to provide them. Relating ableism with the thinking of Judith Butler (2015), it can be affirmed that the practice tends to corroborate the production of vulnerabilities. This is because the binomial norm/deviation, that is essential to ableism, was incorporated in the construction of spaces and in forms of relating that do not embrace human diversity, which makes certain lives unintelligible. One example is the eugenic policies officially instituted in Germany during Nazi rule. Robert Jay Lifton (1986) points out that the Nazi state, based on its ideal of ability, considered disabled people a burden and their lives not dignified of being lived. On this basis, the German government established an official policy that first sterilized thousands of disabled people. Then, under the argument that the death of these groups would be an act of misery, implemented a policy that exterminated more than 200 thousand disabled people, according to data in the Holocaust Encyclopedia (HOLOCAUST ENCYCLOPEDIA).

Gesser (2019) analyzed the implications of ableist norms based on a dialog between the concept of ableism presented by Mello (2016) and the notions of framing and precariousness proposed by Butler (2015). The author highlights that, the effect of framing disability based on these norms includes: a) holding disabled people responsible for their condition and the search for accessibility; b) the construction of strategies aimed predominantly at the suitability of the body to norms that make possible recognizing it as human; c) the accentuation of the establishment of an hierarchy among disabled people, based on the idea of superiority of individuals considered typical/intelligible from a normative perspective, given that, for some bodies, intelligibility, due to the norms, is not something attainable, since they are objects of medical interventions to “correct” the supposed deviations; and d) the emergence of a precarious condition, given that the nation-

⁹ Agency is understood here as the capacity to produce fissures in social determinations constitutive of subjects and their context.

state is not required to guarantee the suitability of spaces based on corporal variations. Therefore, ableism corroborates to make certain lives more or less intelligible and worthy of policies aimed at guaranteeing rights.

Ableism was appropriated by neoliberal government to, in alliance with “familism”, attribute responsibility for the care of disabled people to their families. The narrative that disability is an isolated incident — circumscribed in the body of an individual — together with the narrative of the family as provider of care and of women as those who should provide it, strongly delegitimizes the struggle for this right in the public realm and makes precarious the life of disabled people and their families.

During the Covid-19 pandemic, ableism and familism implied a lack of consideration for disabled people in emergency plans prepared in a wide variety of countries. Until now, little is known about the reality of these people during the pandemic, which involved more effective responses to healthcare, to care in general and to the rights of this portion of the population. Nevertheless, it is known that the impacts of the pandemic were enormous, including traumas and stress within the community of disabled people, as well as “rationing and a lack of capacity in healthcare [services], isolation and deaths and disease among dear ones and members of the community (...), in addition to the expansion of the problems and barriers faced by disabled people who suffer interpersonal violence” (Jorge Henrique SALDANHA *et al.*, 2021, p. 17). To deal with the issues raised until here, below we address some elements of Disability Justice that support the struggle for care as a key political value that should be effectively incorporated by public policies.

Public care as a matter of Justice

In this section, we address the contributions of Disability Justice to producing fissures in the ableism that is widely present in the construction of social spaces and the establishment of modes of relating to disability and to challenging the familist perspective of care. We believe that Disability Justice makes a rich contribution to the qualification of the struggle for care for disabled people who live with complex dependency and who require relations of interdependency, so that they can have agency.

The concept of Disability Justice arose from activism in defense of disabled people, and was initially conceived by Patty Berne and Mia Mingus, who are non-white (black, brown and Asian) queer, women with disabilities from the San Francisco Bay region of the United States. Later, they joined the activists Leroy Moore, Stacey Milbert, Eli Clare and Sebastian Margaret.¹⁰ The group recognized advances made by the movement to defend the rights of disabled people, but perceived that a legal structure based on rights is not always accessible to all people and did not feel sufficiently represented. The movement was mostly white, heteronormative and did little to question racist, ableist and cisheterosexist social structures (Leah Lakshmi PIEPZNA-SAMARASINHA, 2018; MELLO *et al.*, 2021).

Mia Mingus (2018) and Sins Invalid (2019) emphasize that ableist supremacy, white supremacy and cisheteropatriarchy, colonialism and capitalism work together to oppress people marked by these multiple intersections. Piepzna-Samarasinha (2018, p. 23,) affirms that because of this intersection among oppressive systems, the focus on the change of laws as a central solution to the problem of ableism should give space to “a vision of liberation that understands that the state was built on racist, colonialist ableism and will not save us, because it was created to kill us”. It is thus essential that perspectives on disability incorporate multiple intersections to comprehend the phenomena, so that bodies marked by various systems of oppression move together, without leaving anyone behind.

To encompass the multiplicity of disabled people, Patricia Berne, Aurora Levins Morales, David Langstaff and the collective Sins Invalid (2018) define disabled justice by ten key principles: 1) intersectionality; 2) leadership by the most affected; 3) anticapitalism; 4) solidarity among different causes and activist movements; 5) recognition of individuals as entire people; 6) sustainability; 7) solidarity among different disabilities; 8) interdependence; 9) collective access; and 10) collective liberation. All of these principles are considered essential by activists of Disability Justice to the construction of a society that, by breaking with the ideal of the independent subject, supports the care for multiple bodies. The principles complement and support coalition among disabled people and of them with the allies in the anticapitalist struggle.

We will not discuss each of the principles mentioned above, despite their clear importance, but only a few, because of their closer relationship with the issues of care for people with complex dependency. This is the case of the principles of intersectionality, anticapitalism and collective access. The latter is very close to the principle of interdependence — given that the construction of strategies focused on guaranteeing access is always relational.

¹⁰ The precursors are mostly artists linked to the collective Sins Invalid. This is a performance project led by non-white people with disabilities, who address issues such as sexuality, incorporated experience, and disabled corporalities.

Patricia Hill Collins and Sirma Bilge (2020) reveal the importance of the concept of intersectionality as a powerful analytical tool for the study of social inequalities, given that it provides elements for understanding the fact that different people are positioned in different ways in society, based on socially constructed and disseminated ideas about race, gender, class, age, and ability, among others. The concept also allows perceiving how some groups have their vulnerabilities intensified by changes in the global economy — as is the case of the migrant population, refugees, black people, economically disfavored groups, and disabled people — while others disproportionately benefit from these changes. Intensified vulnerabilities imply an increase of need for care.

The analyses of Eva Kittay, Bruce Jennings and Angela Wasunna (2005) point to the fact that there is a restriction of access to care services for a large part of the population in third world countries at the same time that there is a devaluation of these services in developed countries such as the United States. In this country, care workers are usually black and poor women, and many of them are Latin and Africans from the Global South. The restriction of care to the private realm and its identification as a female activity allow its devaluation at the same time that it gives privilege to people with high purchasing power, who are accustomed to having their needs for care provided through the hiring of services (TRONTO, 1993). Without care guaranteed by public policies, the increased precariousness of the lives of disabled people and the lower classes increases exponentially. Anticapitalism combines with justice for disabled people, because it does not exclude people with corporalities that are dissonant from the standard required by the system. In capitalist societies, the status of a citizen is confused with the “independent subject” who has a salary, is a consumer, and “pays his bills”, which includes being a beneficiary of care in the domestic realm or a purchaser of private services. Moreover, the demand for care in situations of complex dependency can be seen by the state as “a waste of money” and a “social burden”. This is because, from a market logic, people who require this care do not contribute in the same terms as others to strengthening the capitalist system.

Collective access to goods and services of care, and to social institutions established to guarantee the well-being and care of so-called independent citizens, must be guaranteed for the entire population and particularly those with complex dependency. Collective access expands the universal design, by criticizing the non-relational and intersectional character that it now has.

Disability activists such as Mingus (2018) and Camila Alves (2020), have been denouncing that the provision of resources for accessibility, although essential, are not enough to guarantee the participation of disabled people in public life, especially those with complex dependency, given that access has a relational dimension that refers to the encounter with the other. Beyond assistive technology resources, Mingus (2017) affirms that an “intimacy of access” is needed, a transformation of the common forms of access for disabled people: from tools to reinforce inclusion/equality into “tools of liberation”. This means guaranteeing that people with different corporal and sensorial marks can be fully involved in collective spaces and feel like they are part of them and not a burden or part of a mandatory rule for accessibility. As Mingus affirmed (2017), this does not involve simply entering the ranks of the privileged, but that “we want to challenge and dismantle those ranks and question why some people are consistently at the bottom”. The intimacy of access shifts this access to beyond the sphere of logistics and positions it in the sphere of relationships. “Access intimacy is shared work by all people involved, it is no longer the familiar story of disabled people having to do all the work to build the conversations and piece together the relationship and trust (...) in order to survive”.

Mingus (2017) also emphasizes that for disabled people to be fully involved in spaces it is necessary to challenge the historic ableism and isolation they experience, especially those who are part of other oppressed communities. Thus, intimacy of access is interdependence in action, which implies convoking people without disabilities to inhabit the world of disabled people. It is equally important to value disabled people for what they can do and offer, in contrast to the dominant narratives that see them as a burden.

The theme of access is intimately linked to that of care as a public and collective responsibility. In the logic of care, the need for social conviviality and access to collective spaces is as important as the material needs for food, rest, health, and relief from pain, for example. Making it possible for disabled people to live in integration with society is one of the objectives of care, as indicated in the introduction to this article, and a demand of Disability Justice.

Final considerations

The objective of this text was to problematize care for disabled people who experience complex dependency and defend it as a question of justice. Our analyses were based on a dialog among disability studies and an ethical political-feminist policy of care. They indicate that it is not possible to guarantee the rights of disabled people who experience complex dependency without breaking with the ableist and familist policies, which are reinforced by neoliberal governments.

The familist-ableist posture of a state at the service of the market and white men with strong purchasing power leads to the confinement of disabled people to the private realm and to the lack of public policies that guarantee care and Disability Justice.

Care services and activities are devalued and made invisible, leading to a broad range of inequalities and injustices that range from excess work for women and the exploitation of racialized people and migrants to the suppression of the needs for care of citizens considered to be “independent” and a set of state guarantees for bodies considered to be “productive” according to an ableist-capitalist logic. This inequality became visible, for example, during the Covid-19 pandemic, in a context of the public healthcare emergency. Rosemary Kayess, vice-president of the United Nations Committee on the Rights of Persons with Disabilities, denounced the phenomenon of exclusion of disabled people from the response to the pandemic, an exclusion that resulted in

Pre-existing inequality and discrimination based on ableism, [and] the view that disability is ‘abnormal’ and able-bodied is ‘normal’. This devaluing of people with disabilities is embedded in law, policy and practice, prejudicing the decisions about who is deserving of critical health care and life saving measures, (UNITED NATIONS, 2020).

Intersectional and relational issues are not considered, nor is complex dependency, and there is no possibility to choose a care provider from beyond the family realm or for public support for active care providers.

In contrast, Disability Justice can qualify proposals in the realm of care for disabled people who experience complex dependency. The feminist, anti-racist, anti-ableist and anticapitalist principles of this theory reiterate the ethical-political commitment to not leave any body or mind behind (SINS INVALID, 2019). Finally, for the implementation of more just social practices, it is urgent that care be assumed as a central value of public policies and that the objectives that guide it and the practices that are specific to it are at the service of the entire population. Only in this way will we have a just society that shelters the multiplicity of bodies and minds.

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