

# DEFIÇA PORTRAITS: DISABLE-CENTERED ART AND ACTIVISM<sup>1</sup>

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This dossier results from a partnership between Western University, Ateliê Ambrosina in Maceió, Brazil, and the Federal University of Alagoas. “Disability Portraits of Brazil” is a research-creation project with the objective of portraying the country from a dialogue with infamous bodies and minds. It claims a collective and geopolitically heterogeneous representation of Brazilian society in the face of disability. According to Lobo (2015), infamous existences are those that occupy, in a contradictory way, the socially recognized registers to tell the history of Brazil. Contradictory because their presence is essential, but their existence does not count as an interested party in the official narrative. They are existences whose appearances must be dehumanized to serve as a constitutive exterior to national identity symbols.

Following the centralization proposed by Lobo (2015), we focus on disability from its potential to bring together other invisible and depreciated existences on how we imagine the nation. The necessary intersection with markers of race, class, sexuality, and region evoked by the plurality of disability experiences, helps us to reflect on the repetitions and circularity of our imagery and narrative repertoire. Thus, by claiming the inclusion of disability in our portrait of Brazil, we evoke an anti-eugenic imagination in which “dysfunctions,” “divergences,” “sequelae,” “pains,” and “discrepancies” are recognized as an inalienable part of our bodies and minds, also as contemporary conditions, rather than an expression of the abnormality we wish to overcome.

Within the scope of this endeavor, disability is not an object of study; it is not a category of analysis, nor does the condition of otherness define this exercise as anthropological. It is a combative ontology (MAFEJE, 2008; 2020; BORGES *et al.*, 2015) through which we question the

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ethical and aesthetic conventions that separate science from activism, art from unique experiences, and interaction from communicative action. By proposing the concept of combative ontology, South African anthropologist Archie Mafeje challenges us to incorporate into our analyses a reflection on the timely effects of the “ideology of tribalism” fostered by anthropologists in consolidating a colonial legacy on the African continent. Here, we present this legacy in close relation to the practices of disability activists in opposition to biomedical and psycho-sociological knowledge. Seeing disability as a combative ontology implies calling on the critical gaze of disabled people to qualify anthropological theories.

Thus, we claim disabled peoples<sup>4</sup> signatures in the images and narratives produced by them, with them, about them or through their bodies and minds. We emphasize the presence, imagery, and narrative performance of socially challenged bodies to place under suspicion the exogenous descriptions of unique experiences with disability. We use Brazilian sociologist Lélia Gonzalez’s (1989) notion of “expressive boldness” to characterize the verdict<sup>5</sup> of those who do not control how “they are represented” by Brazilian social scientists, often appearing in academic texts as objects of study, but rarely as protagonists of scientific practice.

Based on Mello’s (2019) suggestion, we defined the image and sound portraits produced by the project “Disability Portraits of Brazil” as “defiça portraits.” In addition to receiving credit for their participation, we recognize the authorship of the disabled Brazilians participating in the research. That offers us a new framework for our research, capable of valuing the stories of socially challenged bodies and, at the same time, accommodating less conventional perceptions. *Defiça* is an abbreviation of the Portuguese term *pessoa com deficiência* (person with a disability). It has been used in Brazilian academia under Mello’s support and in cyberactivism by *media influencers*, on *YouTube channels*, *Instagram profiles* and *blogs* aimed at disabled people, operating as a formula for positive action and self-affirmation. According to Mello, its advantage is that it allows us to intervene in the Portuguese word *deficiência* (deficiency), which, in her opinion, inadequately translates the English term *disability*, linking the sociological debate to the biomedical approach. Supported by the “*teoria aleijada*”

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<sup>4</sup> In Portuguese the common terminology is “*pessoa com deficiência*” (person with disability) following terminology of the UN convention on the rights of disabled people but we translated here as disabled people, given this is the more common usage of English-language-speaking disability activists and disability studies colleagues.

<sup>5</sup> The term verdict here is used in reference to Franz Fanon's (2022) analysis of the position of “wretched of the earth” used to reflect on the subjective experience of people enslaved during the transatlantic trade and their descendants. The theoretical approach is justified by the inescapable relationship with biomedical knowledge from which disabled people subjectively constitute themselves.

(crip theory) formulated by Marco Gavério (2015), she argues that the term *defiça* can be used as a way of “cripping”<sup>6</sup> this official terminology of its pathologizing legacy.

The “*teoria aleijada*” proposed by Gavério (2015) derives from the North American Crip theory formulated by Robert McRuer (2006) and deepened by Kafer (2013), which takes the bodies of disabled people as spaces of resistance to the conventions of bodily normality. As an analytical tool, its potential is to question the stability and naturalness of non-disabled bodies. By asking, “Who’s afraid of a crippled planet?” Gavério twists the subjectively tragic and economically burdensome discourse that presents disability as a problem for the country and challenges critical social thinking to include disability as a key to understanding social dynamics and inequalities. For this introduction, we are interested in the centrality given by Gavério to corporeality in its epistemic dimension as problematic and inseparable from the research process centering disability. Adding to the reflective understanding of Fremlin (2011), Gavério (2017) asserts the co-dependency between corporeality and the knowledge produced from the disabled body minds.

We extend *defiça*’s meaning as a deliberately crippled way of talking about disability first to the imagery and sound portraits and now to bring together the articles gathered here. We do so because we believe that, in addition to choosing the correct word/theory, it is necessary to act in the world to destabilize the social conventions that depreciate people due to morphophysiological variations (DIAS, 2020). The articles, reviews and visual essays that make up this issue of *Revista Mundaú* responded to our invitation to enhance ethnography and disability’s appropriation as research tools, strengthening ties with experiments in arts and communication.

In addition, it should be noted that in recent decades, not only anthropologists have been writing ethnographies but also activists, artists, and professionals from different areas. Regarding research on disability in Brazil, people who live with bodily and/or cognitive differences have appropriated themselves of this tool as a form of existence, policy, and knowledge. However, this fertile academic debate has little dialogue about how to represent disability in terms of public images and narratives. Therefore, we direct our call for heterogeneous contributions (in the form of articles, visual essays and reviews) by researchers who also work outside academia, such as activists, artists, and communicators interested in sharing the following challenges: 1) visibility and occupation of public spaces and languages

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<sup>6</sup> In a more recent publication (MELLO; AYDOS; SCHUCH, 2022) focused on the questions that disability poses to anthropology as a discipline, the term *defiça* appears as a more attractive form of identification for new generations of activists, also associated to the aim of “cripping” the anthropologies that is enunciated in the dossier’s introduction.

through a *defiça* presence, despite the challenges, barriers and accessibility demands; 2) the expressive valuation of those bodies and minds that escape the conventions of normality; and 3) the construction of multimodal narratives that broaden the perception of the vitality of the experiences of disability, chronic illness and aging.

We want the pieces gathered here to be received as *activist affordances*, that is, as resources, improvisations, or activist contributions (DOKUMACI, 2023). In her recently launched book, the Turkish-Canadian anthropologist invites us to reflect on what disability activism means and the heterogeneous ways in which disabled people and their families can design more livable worlds. Dokumaci helps us deepen the reflection on activism in Brazil, escaping from an analysis based on organized action (in militancy networks, associations, NGOs) for collective purposes or unreflectively focused on implementing public policies. How she tells stories about living with chronic pain (caused by different types of illnesses and disability) and allows us to unveil invisible techniques, situational adjustments and repositioning of people as accessibility resources. In this everyday activism, these articles and our *defiça* portraits can operate as social technologies. Before introducing each piece, we will briefly contextualize the contemporary anthropological work that gave rise to the dossier.

## ETHNOGRAPHY AS A COLLABORATIVE RESEARCH PRACTICE

The co-creation of visual and sound portraits can be defined as a form of ethnographic experimentation in tune with other anthropological practices in contemporary Brazil<sup>7</sup>. As researchers, we carefully developed a structure that could support the creative engagement between researchers, activists, journalists, and artists. We also organized, from a practical point of view, the possibilities of engagement and mutual displacement between people with and without disability. We delimited some conditions for this “doing together”<sup>8</sup> of visual and sound portraits in which the authorship and protagonism of disabled people was confirmed through

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<sup>7</sup> Examples of this are projects aimed at transforming relationships between scientific and traditional knowledge (CARVALHO; VIANNA, 2021; BARBOSA NETO; ROSE; GOLDMAN, 2022) as well as actions that claim for a public anthropology (FLEISCHER; MANICA, 2021; GRUNVALD; REIS 2021) and specifically aimed at disability (CODEA-ABA, 2020).

<sup>8</sup> Although anthropology progresses timidly in relation to collaborative practice, there is a solid basis for experimentation with “doWITH” and “researchWITH” in Brazil’s psychology field. See Silveira, Moraes and Quadros (2022) and Quadros, Moraes and Bonamigo (2019). We observed a convergence of these experiments with the participatory and emancipatory research model advocated by Block, Skeels and Keys (2006), with updated reflections in the article written by Pamela Block in collaboration with Sini Diallo, Block (2020) — a reference for the dialogue between anthropology and disability activism in North America.

the equivalence between technical and aesthetic decisions (ALVES, 2020) employed in the creation and expressive performance of bodies and minds represented.

Following Garland-Thomson (2011), we chose the portrait as a key concept to structure visual and sound narratives due to its performative potential and agency as a public object. For Garland-Thomson, this canonical way of assigning “value” to bodies operates as a collective learning of discernment between the body parts that can be displayed, at what times and for what purposes. Like freak shows and beauty contests, portraits train collective sensitivity through expositive ritualization (GARLAND-THOMSON, 2008). In the international space, between behavior choices of staring or looking away and the body-reflective displacements that the presence of disabled people promotes in public spaces, the portraits can act critically and, at the same time, restorative to the history of segregation and confinement of disabled people (GARLAND-THOMSON, 2011).

Teixeira (2021) uses photo collage as an ethnographic practice in collaboration with disabled women in Maceió, demonstrating this tool's plasticity. By delving into the ethnographic and expographic narrative and how each of her interlocutors engaged in the making, exposition and commercialization of portraits, she explores the existence of portraits and their activist potential as an event in women's lives, as an art object and as an imagination of themselves. Through this research, Teixeira goes further into Garland-Thomson's (2009) “staring” theory, dissecting some components of the gaze to which the bodies and minds of Brazilian disabled people are exposed. At the same time, Teixeira highlights portraits as conducive objects open to collaboration while working with and through images. Although our objective is not to resume the reflection accumulated by visual anthropology, we take advantage of the methodological space it inaugurates as a possibility of coexistence between two visually antagonistic movements: holding a gaze and staring back.

One of Teixeira's photocollages (2021, p. 80) inspired us to visually and conceptually synthesize the project's objectives. The impact caused by the medusa as the project's logo and the engagement it provides opens space for different forms of displacement based on corporeality. In the foreground, our intention is precisely to petrify the moment of interaction to encourage disabled people to “stare back.” At the same time, we are interested in challenging nondisabled people to consider what would happen if, instead of avoiding or deviating, we hold our gaze and move towards this approach. Following Teixeira (2021), we believe the portraits' agency as works of art or capable of operating in the field of desires and conventions as a technology of influence and enchantment (GELL, 2018). Thus, the opportunity of co-creating

portraits can be used to reposition *defiça* bodies and minds in singular interactions and the social imaginary from its broader dissemination.

Contrary to academically strict designs – which are also necessary to expand the spaces and conditions of dialogue between researchers and disabled people — we chose to mobilize with the social movement, especially with the feminist activism of Ateliê Ambrosina in Maceió and the national articulation of Abraça — Brazilian Association for Action for the rights of Autistic people. In other words, instead of investing in our network of “disability<sup>9</sup> ethnographers,” we moved towards what was already being done by disabled people regarding art, research, and shared narratives about disability. People interested in our idea challenged our methodological proposal based on their artistic and communicative experiences and ways of doing based on extensive and heterogeneous networks of interdependence. As soon as we started receiving applications, we needed to review some of the pre-conditions established for the creative process. “Does the duo need to include a person without a disability?” was the question that the activists of the NGO Abraça posed during the mobilization and whose reflection we would like to deepen here<sup>10</sup>.

Of the twenty-two portraits that compose our project, ten were created by duos in which both people were *defiça*. These duos were formed from relationships between siblings, lovers, friends, members of the same association, and partners in the artistic or communication environment who preferred to create among themselves rather than partner with non-*defiça* people. An emblematic example comes from the experience of Júlia Beck, a visual artist from Alagoas, who initially presented herself as the “non-*defiça*” person of the duo. She intensely lived the creation process of the interactive art “*Retrato no Escuro*” (“Portrait in the Dark”) as an artistic practice and an opportunity to perceive herself as a woman with low vision. This dimension of the creative process was explored during the meeting when we received the portrait. She said that although she and her brother have been living with congenital glaucoma since childhood/adolescence, even growing up with this perspective of her “being the next in the family” to “lose her sight,” she nurtures an expectation that she would not go through that.

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<sup>9</sup> We refer here to the history of working groups and round tables about disability that, since 2014, have been bringing together ethnographic research in anthropology, sociology and public health congresses (DIAS, 2020).

<sup>10</sup> The first reading of the project “Disability Portraits of Brazil” was done during the meetings of the Group Realities of Disability in Brazil, funded by the Wenner-Gren Foundation in 2020. We want to acknowledge the generous contributions of Sophie Williams, Helena Fietz, Bernardo Oliveira, Eliza Williamson and especially Valéria Aydos, who intermediated the contact with the NGO ABRAÇA, was the co-creator of one of the sound portraits and personally encouraged several co-creative duos to approach the project.

Until that moment, to perceive herself as a person with low vision was incompatible with her dedication to the visual arts and her artistic identity. Although this project is limited to following her subjective process, it is significant that at that moment we received the interactive art “*Retrato no Escuro*,” Júlia evaluated the possibility of a new portrait, now about her, with her perspective as a woman and visual artist<sup>11</sup>.

We designed a website as an exhibition space where this repertoire can exist as an alternative to biomedical, charitable and overcoming representations of disability. In these terms, the research-creation projects itself into the future, seeking audiences interested in receiving *defiça* bodies and minds as an affirmation and a transforming power of social life. Our fieldnotes are records of these socio-digital connections that were constituted and/or intensified from September 2021 to January 2022. The authorship of these records is heterogeneous: some were made by the researchers, others by the Ambrosina team during the collective and private meetings with the duos, and others were made available by the creators as a record of the duo's meetings and individual creative processes. It continues to be written and recorded in images as new opportunities for exposure and propagation emerge from contact with the website and other possibilities for public presentation of the results.

It is essential to highlight that the project was conceived and developed during the COVID-19 pandemic, considering the need to adapt research practices to sanitary measures to contain the virus, especially physical distancing. In this sense, the project joins other initiatives to bring knowledge production closer to the materially heterogeneous responses that disabled people produced in the face of the pandemic, immersed in their contexts of vulnerability and care networks (MEINERZ; ALLEBRANDT; VASCONCELLOS, 2021).

In addition to circulating in the country, we imagine that these portraits also need to circulate outside Brazil, more specifically in North America, for two main reasons: a) due to the effervescence of *Disability Art* in informing disability justice discussions in both the US and Canada; and b) to break the anthropological theories' logic of reproduction. We are used to seeing researchers from the global north recognized as authors for their theoretical contributions to the discipline. While activists, other social actors and even anthropologists from the “places” where the research takes place are presented exclusively as objects of study. Without intending to reduce this criticism, we are interested in deepening the topic on the

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<sup>11</sup> In the aforementioned portrait, available at <https://www.retratosdeficas.com/angelo-julia>, we have a tactile approximation of objects, sounds and concepts available to be scrolled through with the mouse, composing a biographical chain of Angelo Beck's daily life. It is important to highlight that the essentially interactive quality of this portrait makes following the life trajectory just one of several possibilities for scrolling through the screen (Beck; Beck, 2021).

recognition and circulation of scientific productions on disability that do not come from the Global North.

In this sense, Hellen Meekosha (2011) invites us to reflect on the correlations between colonialism and disability. The author highlights that disability studies were built and continue to expand and be improved in Europe and North America without considering the experiences lived by disabled people and the knowledge produced on the subject from the Global South. More than that, according to the author, most researchers exempt themselves from any critical reflection on the nature of north-south interdependence regarding the reason between causes, frequency, and population distribution of disability on the one hand and global economic and developmental policies on the other. Calling on other researchers from the Global South to guide a critical formulation of disability theories, Meekosha deepens the argument that concepts such as injury, chronic illness, dependence, and care formulated from experiences in the Global North cannot be generalized to the realities of the Global South. In her analysis, the history of colonial, racial and gender violence in the countries of the Global South needs to be recognized as constitutive of the epistemic provenance of European and North American countries, whether in the biomedical or socio-anthropological and activist fields.

Another perspective, by Lopes (2019), explores the complexity of co-production processes between disability and poverty in South Africa, highlighting how racial, spatial, and political dynamics permeate the offer and access to *disability grants* in the post-apartheid South African context. In a less hopeful approach (than Meekosha) of the conditions of dialogue between those in the Global South and those occupying the “periphery of privilege,” the author makes comparative approaches between Brazil and South Africa. The reflections proposed by the author are consistent with our analysis of the contribution of “*defiça* portraits” as a form of resistance, affirmative response, and the political and theoretical potential of images produced in co-authorship and co-creation.

To end this digression on ethnography as a contemporary anthropological practice, also resuming our objective of summoning disability as a combative ontology to think about the interweaving of infamous existences in Brazil, we reproduce an excerpt from Pedro Lopes' conclusions in his comparative analysis with the African country:

In other words, when we think of disability and poverty, it is not just a vicious circle of precariousness and deprivation but historical trajectories that are produced in the articulation between other axes of difference, such as race, class and health, as well as building the nation at the same time that they are constructed about it. (LOPES, 2019, p. 12).



The co-creation of portraits of a Brazil that wishes to recognize disability as part of its history and identity has a double claim. Of presenting as an alternative to the opportune and circular enunciations that make up the Brazilian imagery and narrative repertoire, in which disabled people are “spoken about” and “used” in scientific images without their knowledge. And at the same time, to interfere, albeit timidly and incompletely, in the self-referential flow of theoretical and artistic productions on disability in the Global North.

## *DEFIÇA'S PORTRAITS*

Some of the articles and visual essays presented in this dossier are the result of a creative deepening movement through a series of four thematic symposiums held between 2022 and 2023 with funding from the Social Sciences and Humanities Research Council in Canada, and the Wenner-Gren Foundation in the USA. Our main aim was to put the Brazilian *defiça* portraits' creators in contact with researchers, artists, and communicators in Canada and the United States. The symposium participants joined in synchronous virtual conversations with the authors of at least two co-creations from our virtual gallery/podcast. The themes of each symposium, developed from the initial round of co-creation, were: 1) Activism, Disability and Indigenous Identity in the Anthropocene; 2) Sexuality and Gender; 3) What Visibility Do We Want?; and 4) Art and Access: Between Technique and Aesthetics<sup>12</sup>.

The articles by Passos (2023) and Silva and Pereira (2023) in this dossier provide significant examples of deepening the discussion on visibility from a disabled-centred perspective. Passos (2023) shares their drawings of naked disabled bodies, challenging the body normality, an aesthetic apprehension of atypical contours. At the same time, drawing himself and other disabled people, he problematizes invisibility as a mark in the lives of disabled people. A self-narrative movement in which he invites disabled people to get rid of the exogenous looks that deform their relationship with their bodies. Silva and Pereira (2023) discuss the relationship between cinema and knowledge production, considering Silva's documentary on the experiences of Brazilians with intellectual disability during the COVID-19 pandemic. The documentary is a keen reading of how disabled people “disappeared” from public policies during the Bolsonaro administration, especially in the face of the (mis)government of the pandemic.

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<sup>12</sup> We would like to thank all the researchers, students and volunteers involved in organizing the project *Retratos Defiças: Arte, Deficiência e Comunicação* (Disabled Portraits: Art, Disability and Communication). Especially the partnership of Marivete Gesser, coordinator of the Núcleo de Estudo da Deficiência (NED) at the Universidade Federal de Santa Catarina (UFSC). To the students from Western University: Mathew Medeiros, Paloma Terra Figueiredo and Lucas Besen. And also to Giovanna Nicolau, Diego Ferreira da Silva and Sindy de Freitas de Alencar.

Amato's (2023) review of *The Right to Maim: Debility, Capacity, Disability*, by Jasbir K. Puar, deepens the analysis of disabled bodies and governmentality. In this review, Amato highlights the contextualization of neoliberal policies as a condition for analyzing which subjects and bodies are worthy of having their fundamental rights assured.

Following the critical apprehensions of diagnostic centrality based on the experience of disability, Nicolau and Assis (2023) address how the categorization of autism was “colonized” by non-autistic specialists. Notions of who is or is not autistic are often limited not only by shifting clinical categories that autistic people do not control but also by conceptions tied to whiteness that operate in conformity with other colonial legacies. In this sense, the dossier allows us to deepen the articulation of disability with different intersectional categories to problematize the performances accepted or rejected within a sociocultural context. Hilgemberg's article (2023) resonates with the theme of the visibility of disability on digital platforms, showing how an athlete with a disability is represented as a normalized and sexualized being in the popular cultural imagination. The visual essay by Rouse and Lo (2023) explores intersectionality from another framework, offering an unconventional possibility of appropriating visuality. Starting from the experience of deafness and bodily communication, the authors allow us to observe sound and how it unfolds in space. *Chaotic Expressions* is an intersectional manifesto for repositioning vision within the realm of multisensory experience. Movement is precisely placed at the center of our expressive capacity because it reminds us that we are constituted as subjects in multiple ways.

Katzman and Chatterjee delve deeper into the intersection of disability, gender, and sexuality by demonstrating how these categories can be used to include or exclude people from social acceptance and academic recognition. Katzman (2023) discusses the potential of the non-binary identity of a person with a disability and asks: Can disability be a non-binary experience in the same way that we consider gender contemporaneously as non-binary? General understandings define when someone is or is not a person with a disability. Still, many people (including Katzman) feel they occupy a space between these categories and challenge our understanding of boundaries, especially when these are constructed through falsely simple oppositions.

Chatterjee (2023) discusses the possibilities for people who are neurodivergent, queer and/or trans, femme, or others whose self-expression is intersectional to transcend gender, caste, and disability identities. While there are spaces for people who hold some of these identities, maintaining these multiple identities can often be lonely and even dangerous, as they are seen as particularly threatening. Teixeira (2023), in “Ensaio Visual Deficiena,” also invites us

to problematize the regulation of femininity from an intersectional point of view without verbally articulating gender, race, sexuality, class and generation categories. In an ethnographic context, the photocollages co-created with *defiça* women from Maceió disassembles these concepts based on thinking with and about the images.

We end our introduction with publications that explore the interactions between art and disability. In the article "*Misfits in the world: Culture shifting through crip cultural practices*," Chandler *et al.* (2023) discuss art as a culture of disability and the construction of the world. Not accepted in conventional spaces, disabled artists create new spaces and, at the same time, push for access to spaces traditionally excluded during the COVID-19 pandemic. The urgency of interrupting the flow of exceptionality has also creatively affected anthropological research in the sense of thickening research WITH strategies. In Costa's Visual Essay (2023), drawings are presented as a form of sharing writing fieldnotes. "Fable with dementias" is a powerful metaphor that allows the researcher to actively engage in the tensions and daily accommodations of the care and the making of dementia in its different experiences — individual, family and institutional.

The problematization of care based on feminist criticism has also found fertile ground in the universe of artistic photography. Through the review "Retracting Relationships, Remaking Worlds: disability and care in Ana Álvarez-Errecalde's Photography," Aureliano (2023) invites us to delve into the political power of the aesthetic choices made by the Argentine photographer. She explores the images produced with different Spanish families, including those of the book's author, who live with complex and intensive care demands. Portraits details the scenarios and relationships in the portraits, as well as the lived experiences of the families on care practices of adult and elderly members (affected by degenerative diseases, rare diseases, and intellectual disability). Highlighting it, Aureliano returns to the question with which we started the project: to make people think about what confers value to bodies, and what makes them worthy of public attention.

We hope this dossier is just the beginning of the conversation about activist and academic collaborations between disabled people in Brazil and Canada. People are using new terms like *aleijado* (crippled) and *defiça* (disabled) in different ways and for different purposes, and we are happy to be part of this conversation to rearticulate representations of disability in Brazil.

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