

Idealization, Coordination and Research Jialu Pombo

Participant Authors
Ber Kroeff
Carol Cardoso
Jialu Pombo
Natana Magalhães
Tao Itacaramby
Tom Nóbrega

Design Lázaro Mendes

ProofreadingTom Nóbrega

English Version Tom Nóbrega

Audiobook Ber Kroeff

This project was carried out between April 2022 and January 2023, through the **Crea**te Initiative, from Creating Resources for Empowerment in Action (Crea) - a feminist human rights organization.

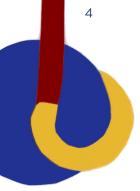


contents

Foreword	
Disability and diversity among social	
dynamics revolving around visibility and invisibility	4
Personal stories	
Carol Cardoso	26
Jialu Pombo	31
Tao Itacaramby	35
Ber Kroeff	40
Jialu Pombo	43
Tom Nóbrega	46
Natana Magalhães	50
Jialu Pombo	54
Glossary	58

61

References



foreword

DISABILITY AND DIVERSITY AMONG SOCIAL DYNAMICS REVOLVING AROUND VISIBILITY AND INVISIBILITY

Motivations and pathways

The main goal of this booklet is to increase awareness about that which we call "invisible disability", by raising questions and making propositions that might help us think about the topic in its **intersectionality**¹ with issues related to both gender and sexual diversity. During our journey, the magnifying glasses of our lenses will be pointed towards **language**, so that we might be able to recognize the pitfalls that make themselves present both in discourses on disability and in discussions concerning gender and sexuality.

The idea of developing this project emerged from the intersection between my social experience as a **transgender** person and two diagnoses that I received in 2020: first, a diagnosis of Spondyloarthritis, an autoimmune disease, and second, a late diagnosis of ASD (Autistic Spectrum

Disorder). In order to elaborate this material, I have invited five people from different regions of Brasil whose invisible disabilities were also uniquely interconnected with their journey with gender and sexual diversity. Our stories will interact with each other throughout these pages.

The unique way through which this intersectionality is experienced by each of us sheds light on issues related to the social dynamics revolving around what is or what is not visible in our bodies and our behavior. The common sense usually associates the notion of disability with elements that make themselves visible in the body. However, besides the fact that, according to the law, the notion of disability goes beyond the notion of physical disabilities, not even the physical disabilities themselves always present visible signs. Although the public debate related to these issues has been maturing considerably, we can still notice the presence of significant gaps both in the conversations and in studies in what regards the way visibility and invisibility manifest themselves in the social dynamics, and to what extent their effects can be felt, both individually and collectively. By looking at these social interplays, we seek to recognize and to understand what invisible disability really means. How widely known is this term to the general population? Are there public policies put in place to offer assistance to the population living within this spectrum? We will be reflecting a little on these questions, before considering how invisible disability relates to issues related to gender and sexual diversity.

A word about the concept of disability

Throughout history, in different contexts, the term "disability" has often been resignified. The very origin and structure of the word allows us to understand the reason why it has often taken on a pejorative connotation: it can be associated with terms such as "imperfection," "flaw" or "defect". Thus, by extension, a person living with a disability

¹ All of the words or concepts appearing in bold in this text can be found in the glossary at the end of the booklet, as well as some words and concepts which are present in the texts created by the participants of the project.

could be perceived as a flawed, defective person. To what extent such a conception remains still deeply ingrained in our society? It is not solely on dictionary entries that this depreciatory connotation makes itself present: the idea behind it has been repeatedly reinforced by institutional state policies. It has often been guiding medical and educational conducts, leading up to a series of physical, psychic, and symbolic violences performed throughout centuries.

This conception related to what would be a "lack of ability" can be linked to a perspective according to which standards of normality could be used to evaluate individuals. Conventional criteria are employed to determine not only the way in which someone should appear physically, but also to evaluate one's psychological structure, as well as one's intellectual, sensorial, and cognitive skills. According to this perspective, whoever diverges from this standard model could be viewed as being defective, an idea that was taken as far as to lead to the understanding that certain beings could be themselves understood as flaws. Anyone who doesn't conform to what is considered normal is perceived as abnormal. This so-called abnormality would often be understood as an inadequacy concerning only the individual, rather than a situation that arises as a consequence of certain models of sociability. This booklet is here to voice a clear NO not only to this alienating approach, but also to the social practices deriving from it.

The material you are about to read was created in alignment with the perspectives of the social movements which have been fighting for the rights of people with disabilities, which has since then been transforming the use of the term "disability" itself. The aim of such movements, which emerged and expanded worldwide during the decades of 1970s and 1980s, was to demand changes in the laws in order to secure the basic rights of people with disabilities. They would seek to guarantee their right to existence, as well as their right to education, health, housing in short, to secure them the same social rights that any non-disabled

person has access to. In the context of these movements, the term disability went through a twist: it started to be employed to qualify the social context which alienates people living with disabilities, rather than the individuals living with such conditions. From then onwards, the issue of disability started to be addressed through a social approach, alerting us to the pressing need to evaluate the way our society is structured: does it in fact provide everyone the possibility to enjoy life with **equity**?

"Disability" is a concept, and, as such, brings up a wide range of issues according to the different context in which it circulates, be they medical, legal, historical, academic, activist, and so on. Whenever we refer to someone as a person with a disability², we are taking into consideration all the multiple spheres through which this word resonates. In the Brazilian context, the use of the term WITH appears to be a crucial one, and therefore became one of the starting points of the reflections proposed in this booklet. As living beings, we create the world in which we live with each other according to our own structuring characteristics. If a certain number of characteristics are recognized as forms of disability, the lack of ability implicit in this word should not be understood as concerning individual existences, but rather referring to the inadequate dynamics of social coexistence which fail to provide favorable conditions of life for the singularities of certain bodies. It is our understanding that all people have inherent value, each and everyone of them with their unique set of stories and experiences. Each body/mind is unique and essential simply the way it is, with both their vulnerabilities and their strengths.

² In some other countries and contexts, however, the term "disabled person", rather than "person with disability", is considered to be a more appropriate expression to refer to this group of people. It should be noted that, while the forms of language considered most appropriate or valid are constantly changing, perhaps the most important lesson to derive from it is that, everywhere, language constitutes a field of dispute. The forces that hold power to legitimate a given word often seek to hinder the use of more equitable and dignified expressions, therefore insisting on keeping in use terms that tend to devalue a certain population.

It is never too much to emphasize that it is crucial to detach the different conditions classified as forms of disability from the undervalued social places attributed to them. On the other hand, it is fundamental to recognize that each of these conditions might produce limitations that affect each individual in a specific way, requiring therefore equally specific forms of care. All along, we should remember experiences of limitation or vulnerability are inherent to every living being. The correlation between limitation and care will always depend both on the peculiarities of the individual experience and on the specificities of the surrounding social context. In a statement made for the documentary História do Movimento Político das Pessoas com Deficiência no Brasil, [History of the Political Movement of People with Disability in Brazil], Lúcio Coelho David shows us why disability might be understood as being situational:

"(...) my disability will either increase or decrease according to the environment I am in. Even though I walk, if you put me in a place full of stairs, without any handrails, my disability will certainly increase. On the other hand, if you put me in a place provided with a ramp, within an accessible context, where the access is easy, then my disability will decrease, sometimes even to zero. So: I'm not the only one who is disabled, the environment is disabled, too."

Such an approach awakens us to the need to reflect about social justice. It is due to unfair social dynamics that certain groups are in situations of disadvantage. In what concerns disability, thinking and practicing social justice requires recognizing the evidence that this society is not structured so as to ensure equity among its inhabitants, and for this reason it is urgent to transform this scenario. In a structure characterized by social equity, diversity should be valued: offering access to those who have been historically and systematically excluded is a pressing need. According to this perspective, thinking about accessibility does not consist in seeking solutions to provide access to individuals who are considered exceptions. Rather the contrary: once public policies start

being structured to attend to diversity, there are no longer exceptions. One must remember, however, that our current reality is still very far from being guided by this perspective. The way our society is organized has often proved to exert harmful effects on our bodies and minds, which might allow us to conclude that adopting standards of normality and/or ability is unsustainable. But is the negative impact these standards exert on our bodies and minds clearly visible? Is it recognized as a problem?

(In)visibility games

Our lives and our social interactions are defined by characteristics that make themselves visible, whether in our physical structure, in our behavior, or in the way our bodies operate. This dynamic is put in motion by unfair social relations generated by oppositions between normality and abnormality, in which those whose appearance is immediately perceived as being divergent from the standard are more likely to suffer with violence and exclusion. As it turns out, not everything that constitutes our experience of the world is entirely visible: the modes of existence that diverge from the prevailing pattern are not always physically evident. In those cases, we encounter an ambiguous situation: on the one hand, we could say that a person whose disability is invisible is to a certain extent more protected than someone with a visible disability, precisely because their condition is not immediately perceptible to others. For this reason, the partial protection conferred by invisibility could be understood as a subtle form of privilege, when compared to the experiences of people with visible disabilities. On the other hand, the very fact that the conditions behind them cannot be inferred from physical characteristics often prevent invisible disabilities from being noticed or even considered valid. In such cases, invisibility eventually reiterates the lack of access.

Oftentimes, a pejorative word is widely adopted and starts being employed as a social and identity category to refer to groups suffering from some kind of oppression. Such cases illustrate how unequal and ableist criteria might become normalized to the point of orientating official state policies, which further contribute to worsen the undervalued situation experienced by these groups. What social movements do, in their turn, is precisely to attempt to operate a twist on certain categories imposed on us: this applies both to the movement of people with disabilities and the **LGBTQIA+** movement. Once transformed through affirmative dynamics, these identity categories might become useful tools that enable us to express ourselves, as well as to counteract the limits that have been forced upon us. For those of us who live with an invisible disability, in particular, making use of these categories might often be an empowering gesture - the act of naming becomes then a vehicle for access. Even while we make political use of these categories, though, we must not forget that our existence goes far beyond any name, far beyond anything that verbalized and intelligible word can encompass.

What is, after all, an invisible disability?

In Brazil, there is no such a thing as a list enumerating the specific conditions that may be considered invisible disabilities. All we can find are some vague citations in a few municipal and state laws seeking to institute items such as a "sunflower collar as an auxiliary guidance tool for the identification of people with hidden disabilities". In countries

such as Canada and England, on the other hand, there are lists⁴ taking account of such a heterogeneous variety of conditions that we are led to question the very boundaries separating the notions of disability and disease. What are the similarities and differences between those two concepts, both in terms of their empirical reality and of that which is recorded in law?

Since the definitions are quite vague, and a complete list is lacking, it is our understanding that a disability does not need to be visible to find support in the LBI - Brazilian Law of Inclusion of the person with disability. In the article second of this law, we read:

"We consider a person with a disability someone who has a long-term impairment of physical, mental, intellectual or sensory nature, which, in interaction with one or more barriers, may obstruct their full and effective participation in society on an equal basis with others."

This is just a small excerpt of a law text which is 31 pages long. Even reading the legal text in its entirety, however, some questions keep echoing: do we, in our everyday social life, know how to identify a "long-term impairment" and the "barriers" that individuals living with disabilities interact with? What would a "full and effective participation in society" look like? Does the notion of "equal basis" advocate for a social perspective based on equity? Do we realize that all these concepts must be understood as they operate in modifiable and situational contexts?

Taking these questions as guides, we must not forget that, even though our country has a relatively well-drafted legislation, many of its determinations are not yet put into practice. A number of the issues related to this topic, though present in the text of the law, are not often discussed in wider circles and remain, therefore, unknown to the general

³ We could cite as examples the Law 5.044 of Guarujá, municipality of Sao Paulo; Law 6.842/2021 of the Federal District; Law 14.239/2021 of Juiz de Fora, Minas Gerais; Law PLL 241/21 of Porto Alegre, Rio Grande do Sul. The sunflower necklace initiative was deployed originally in England.

⁴ Available in the reference list at the end of the booklet.

population. As an example, we can reflect on the notion "psychosocial disabilities", which includes several mental health conditions, such as depression, social phobia and schizophrenia. The expression "psychosocial disabilities" is not directly mentioned in the LBI [Brazilian Law of Inclusion], seeding doubts: which of the conditions it contemplates are in fact included in the group of mental health "impairments"? What would be the differences and similarities between psychosocial and intellectual disabilities? The impairments caused by so-called chronic diseases, such as fibromyalgia, are often similar to those present in many disabilities, though these conditions are not widely regarded as such⁵. Though the Autism Spectrum Disorder has already been considered a disability for legal purposes⁶, this is not the case for Attention Deficit

Hyperactivity Disorder (ADHD) or dyslexia. As for conditions related to the sensory apparatus (such as visual and hearing impairments), though they compose the popular imagery about what disability is, we often do not realize that they might also go unnoticed, since they cannot always be immediately recognized.

It should also be taken into account that, in order to deal with the fragilities of the health associated with disabilities, diseases and/or chronic conditions, many people, throughout their lives, will need to commit to a large number of appointments to proceed with treatments, therapies, and rehabilitation procedures. The time and dedication invested in the complex dynamics of care might prevent these people from living more beneficial and healthier lives, thus generating impairments that hinder their active social participation. To guarantee their rights to receive support in different spheres, it is fundamental that the information about the conditions contemplated by the laws concerning disability be more openly widespread.

Though the discussion about disability raises broad questions about our ways of life as a whole, as well as about the way we interact with each other, it is necessary to think about invisible disability in its particularity. Once we start reflecting about conditions which, though they cause limitations, often remain invisible, we might realize that the number of people with disabilities in Brazil and in the world in general is likely to be much larger than the popular imagination would expect, larger even than the numbers we have registered in Censuses so far. Why are we still stuck with the idea that people with disabilities constitute an exception?

It is necessary to understand that, as long as ableism continues to operate as one of the structuring bases of our society, accessibility will continue to be understood as a mere aid for those who are in situations of disadvantage due to the fact that their bodies and minds would seem

⁵ There are state and municipal laws, such as Law 11.554/2021, from Mato Grosso, that grant people with fibromyalgia the same rights other people with disabilities have. In our research, however, we did not find a national law that directly addresses the rights of people with chronic health conditions; there is no document with the same complexity and scope of the LBI [Brazilian Law of inclusion]. What we found were documents offering guidelines in the health field, such as *The Strategic* Action Plan for Confronting Chronic Diseases and Non-Transmissible Diseases and Guidelines for the care of people with chronic diseases in the health care networks and priority lines of care, which do not have the status of laws and therefore do not list the rights of the population living with chronic diseases. In Brazil, besides the concept of "chronic disease", there is the broader concept of "chronic condition". In addition to chronic diseases such as cardiovascular diseases, cancer, diabetes, and chronic respiratory diseases, which are the ones more often mentioned, the term "chronic condition" includes, for example, persistent infectious diseases (tuberculosis, HIV/AIDS, etc.); conditions linked to maternity and the perinatal period, as well as conditions linked to health maintenance by life cycles. Chronic conditions also include disabilities and long-term mental health conditions, as well as "health conditions characterized as illnesses in which there is suffering, even though they might not fall in the category of illnesses under biomedical standards" as states in the document *The care of chronic conditions in primary health care: the imperative* of the consolidation of the family health strategy.

⁶ Law 12,764, whose name is Berenice Piana Law, sanctioned on December 28, 2012...

to represent "an exception to the rule", or, in other words, "a deviation from the standard". In a context in which the accessibility, when it exists, tends to be addressed only to those whose disabilities are perceptible and apparent, how is it possible to include those whose conditions are invisible? How to recognize an invisible exception? Can't we recognize that the problem lies exactly in the pattern of taking standards as rules?

This booklet was created to remind us that no such a standard exists. Instead, what we have is a rich multiplicity of ways of living and ways of being. The same idea lies behind our understanding and experience in what concerns gender and sexual diversity.

Biased perspectives and a double-edged sword

When we correlate the invisible disabilities with the different experiences of the LGBTQIA+ community, we realize they have also often been considered deviations from the norm. One of the first things we observe in the case of individuals whose experience goes across both fields is that, since their way of living is doubly marginalized and/or ignored, it often leads to a devaluation of life itself. Along with this, comes the issue of language: if, on the one hand, there is a weight in recognizing ourselves as part of a given category, there is also a potency to be found in the act of discovering, transforming and/or creating names for our experiences.

This crossroads sheds light to yet another issue: oftentimes, one's diversity of gender or sexuality might not make itself immediately apparent throughout dynamics of sociability. Here, as it was the case with the invisible disabilities, the gesture of naming and talking about what we are often becomes a double-edged sword: if, on the one hand, it

Research conducted by organizations such as the Observatory of LGB-TI+ Deaths and Violence in Brazil illustrates how the violence against this population might be considered part of a structural context of "discrimination, aversion or hatred, of individual or collective content, based on the presumed inferiority of LGBTI+ people in comparison with **heteronormativity*****. In such surveys, there is a clear discrepancy in the numbers of violent deaths among people of different gender identities and sexual orientations, which is closely related to the greater social exposure experienced by certain groups in relation to others. In the 2021**, survey, we might verify, for instance, that there is a higher number of deaths among cis gay men, travestis*** and transsexual women: these form the majority of LGBTQIA+ people who died from homicides. Travestis and trans women "have been the preferential target of attacks in public spaces, and their social exclusion is marked by obstacles of different natures". There is an associated risk factor: many of them "are on the streets, working in precarious sex work contexts".

- * Deaths and Violence against LGBTI+ people in Brazil: Dossier 2021 / Acontece LGBTI+ Art and Politics; ANTRA (National Association of *Travestis* and Transexual people); ABGLT (Brazilian Association of Lesbian, Gays, Bisexuals, Travestis, Transexuals and Intersex people). Florianópolis, SC: Acontece, ANTRA, ABGLT, 2022.
- ** Until the moment we finished writing this text, the most recent dossier we could find was from 2021.
- *** Brazilian word referring to transfeminine people who have been assigning male at birth, but develop an unique gender identity by exploring different expressions of femininity, which are not necessarily directly identified with the category of "woman"

On the other hand, the numbers of homicides of trans men, transmasculine people, and cis lesbian women is comparatively low, which may be a reflection of the social invisibility experienced by these populations. While these surveys recognize suicide as kind of a violent death, the current data available on suicides committed by the LGBTQIA+ population suggest a gap surrounding this topic in the news and public debate. In none of these surveys, there is any data about disability. Though this is not our main focus, it is also worth noting that the Atlas of Violence only began to include the disabled population in its research as late as in 2021, which highlights the social invisibility of this group. Besides that, it should be noted that in the researches on violence against people with disabilities there is a gender framework that does not take trans identities into consideration.

can enable us to get a social response which is more fitting to our reality, on the other hand, it makes us more exposed, increasing our risk of becoming targets of some kind of violence or discrimination. The reason why such a risk is present is because our model of society is based upon the assumption that **cisgender** identities, heterosexuality and non-disability are the normal conditions: all the others are often disregarded. Our perceptions are biased.

To look at a trans person through such a reductionist perspective, for instance, is to ignore their experience of the world and rend their history invisible, since their experience will never be the same as that of a cisgender person. If looking at a transgender person from a perspective which considers cisgenderism to be the norm configures what we call **transphobia**, looking at a person with disabilities through the same lenses that we would use to look at a person without them configures what we call ableism. Neither the experience of a person with disability nor the one of a transgender person can be described by taking the perspective of any other reality. They can-

not be evaluated according to any generic standards: each social group must be reflected upon according to its own terms, according to its own history. Assumption-bound perceptions often produce social injustice. After all, do cisgenderness, transgenderness, homosexuality, and heterosexuality really show visible signs?

Can you realize how living under a regime of the supremacy of sight might turn out to be a trap? We should also point out that electing a single sensory sense as the main foundation for social exchanges is yet another facet of ableism. We want to contribute to the construction of a world that leaves completely aside the idea of the existence of a typical body/subject. Only then we might be able to develop a true sensibility towards the multiple differences inhabiting and moving across diverse environments.

Gender and sexuality are markedly present in our society, cutting across everything. They appear discreetly here and there, guiding exchanges and interactions between bodies. Throughout history, the experiences revolving around this spectrum, in their multiple variations, have been often considered pathological. They were often understood as diseases to be studied, treated, and even fought against, which constitutes yet another mark they share with the topic of disability. Another element enters this equation, however: the notion of "disease", accompanied by the social perception we have of it.

Depathologizing diversity

To put it briefly, we might say that the notion of "disease" corresponds to a variation in the state of equilibrium of a given organism. It should be, in principle, a temporary variation: each organism should find the path back to equilibrium that works best for itself. There are many reasons why having a disease is considered an unpleasant thing: it can

generate pain and discomfort, and at times even be fatal for the affected individual. It may be a contagious disease, able to be transmitted to larger groups, putting many people at risk at once. It is our belief, however, that one of the striking pitfalls of the social conceptions gravitating around the notion of disease is that, instead of being thought about according to the frame established by the singularities of each individual, it is usually conceived in contrast to standardized states of ideal equilibrium. The balance of each organism should be understood as something unique: any change in this peculiar dynamic should deserve specific attention and treatment.

And here we might observe the intersection between widespread notions of illness and the tendency to perceive the diversity of life as something pathological. We are often faced with treatment protocols whose goal is not to promote the wellbeing of individuals whose body and/or behavior is considered pathological, but rather the maintenance of a normative social standard. The trans population has been fighting against this pathologizing perspective present in manuals such as the ICD7. Jaqueline Gomes de Jesus comments on recent changes in the ICD11: "What I ask is why procedures related to the health of the trans population do not have an ICD code. Hormone therapy for trans women or trans men, doesn't have a code in the ICD, but what does exist is a code for our identities." We don't need treatment guidelines for our identities: we need guidelines for the procedures that will guarantee our health, from basic to specialized care.

Though some disabilities are not related to any alteration in the health, most of them do establish a constant relation with medicine, and almost all of them involve the experience of a diagnosis. The commonsense perception according to which a disease, because it creates limitations, could be seen as something entirely negative, ends up producing stigmas that directly impact the lives of people with disabilities. People with disabilities might often be considered limited even though they are in optimal health, regardless of the fact that their unique organism/existence is in a state of equilibrium.

Western society often refuses to recognize limitation as an integral part of the experience of life. Such an attitude has proven to be extremely harmful both to the social relations and the ecological dynamics of our planet. Precisely for being alive, every being is vulnerable. And this does not make us less autonomous, on the contrary: it can propitiate a kind of autonomy that is collective, that can be shared.

Just like any other condition of existence, neither disability nor gender and sexual diversity, as experiences, can be described only through the limitations they may bring: quite the contrary. Once we accept, recognize, and understand our conditions, we experience a powerful freedom in our relationship with our bodies and our behaviors, a kind of freedom that might not be experienced by the social groups considered to be normal. Expressed through the peculiarities of each condition and each individual, disability allows us to perceive and experience the world in unique ways. This uniqueness propitiates opportunities that unfold in transformative everyday practices that create sets of knowledge that enrich collective life. History is full of examples that make this evident.

⁷ ICD is the acronym for International Statistical Classification of Diseases and Health Problems.

⁸ Text A nova ICD 11 no contexto nacional [The new ICD 11 in the national context], published in the newsletter Transvida 2022 - special edition trans visibility, idealized by Felipe Martins.

The shared autonomy of common people

As living beings, as human beings, there are many things we share in common. For this reason, we often adopt common directions regarding health care, regarding life. Though it can help us find more equitable forms of balance, adopting collective criteria might only prove to be beneficial to us when we are able to recognize the uniqueness of each individual in the course of care practices. The implications of the term "common" are very different from those of the term "normal", especially because its antonym, "uncommon", is not at all associated with pejorative ideas. Whenever we say that something is unusual, we just mean that it is infrequent, which is of course very different from saying that something is abnormal. Words are not just words: they unfold into practices. We need to review our practices.

Whether we, as LGBTQIA+ people and/or people living with both visible and invisible disabilities, are infrequent or not when compared to the general population, it matters little. We are certainly many, both in quantity and in potency. No form of comparison, not even one that seeks to claim that a given group is a minority or majority over any other, can be used to measure lives. What really matters to us is to enjoy life as a "common person", as Rita Lee would say in the song "Nem luxo nem lixo [Neither luxury nor trash]", from 1980. We do exist, and we are common. We are also unique, like everyone else. We are neither an exception, nor an aberration. Neither are we angels or extraordinary beings⁹. This is what it means to be able to imagine a society structured

upon the recognition of diversity. When the diversity of living beings is equally valued, we all become common people.

The word "common" suggests the possibility of creating communities, of living together. We believe it is by living in community that we might acquire real autonomy. After all, no single being is able to remain alive alone. Autonomy is not synonymous with self-sufficiency. The autonomy we propose here can only be possible through interdependence – a potential of yours might bring the answer to a need created by a limitation of mine, and vice versa. This project has created a small community among six common people, each with their own singularities and vulnerabilities; each one of us with their unique biographical, social, and identity marks.

Brazil is a very large, diverse country. In order to weave an encounter with people coming from different regions of the country, an intersectional approach was necessary. We can observe that both the experience of gender and sexual diversity and that of invisible disability unfold very differently when we take into account factors such as race, ethnicity, and class. Other striking differences appear once we when take into account, for example, whether someone grew up in a nurturing or in an abusive family, whether they live in a big city or in the countryside. In this group of six people, certainly a very small number in terms of data collection, it was already possible to observe differences of this kind: the easier access of people from more privileged classes to assistive technologies such as hearing aids; the effects on the mental health of people who are targets of racist violence; the more accentuated social exclusion in the experience of people who come from lower classes. We will let the content created by each participant of this project invite the reader to deepen these intersectional considerations, reflecting on what distances us and what brings us together.

These booklet was created throughout months of exchanges, during which I talked to each participant of the project serving as a guide, sug-

⁹ We might observe that whenever individuals from the LGBTQIA+ and disabled communities themselves choose to make use of terms like these, as well as other words, like "monster," there is once more an act of twisting the meaning of pejorative words previously used to diminish us. When that is the case, the desire not to be normal is often clearly expressed: the choice is to affirm and value one's own difference. These articulations are not contrary to our desire to be "ordinary people": the "ordinary" aspect we refer to here is associated with the notion of social equity and our right to come and go freely, as well as to have an autonomous life that is considered valuable.

gesting which elements of their trajectory could be highlighted in the stories to be shared. Having common mottos as departure points, each person created either a textual and/or an visual content through which they found their own way of addressing not only what they share in common with others, but also what makes them different. Besides the stories written by Carol Cardoso, Tao Itacaramby, Tom Nóbrega, Ber Kroeff, Natana Magalhães and Jialu Pombo, this booklet also presents some biographical elements that emerged during the conversations that took place between June and November 2022.

After all, how does the theme of invisible disability interact with the discussion about gender diversity and sexuality? We could say that both these topics address tensions previously created by social categories, which imprinted names on our bodies. Such names would, from then onwards, shape our exchanges around the world. We are often presented as exceptions: this is nothing but a strategy to rend our existence invisible. As it turns out, rather than being exceptions, we are diversity itself! Our lives unmask games of visibility and invisibility lurking behind a number of social injustices. In this process of disclosure lies our strength.

We hope that the experience of reading this booklet might prove to be enriching. May it mobilize change!

jialu pombo





They have put a label on my existence. If I could simply exist, I would go on existing, anyhow. But in order to go on existing, I must affirm that I exist using names I did not create for myself.

We are always someone else's other.

As historian Beatriz Nascimento says, "In order to recover an identity, one needs an image."



Though I was born in Belém do Pará, I grew up in Amapá, where I lived most of my life, until I migrated to the southeast of Brazil.

In all the spaces I inhabit, people read me in a fragmented way.

There is no space where we can be read integrally.

For us who live with some disability, all this intensifies. Only a few spaces are accessible to us.

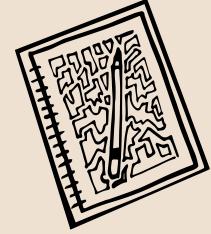


Recognizing my own place means discovering that there can be a room for me in this world, that it makes a difference whether I decide to stay here or to go away.

When I spent some time in a mental health clinic, because of everything that had been staggering me, a psychologist finally understood why I was the way I was. She said that I was autistic, that I had what people used to call Asperger's Syndrome.

Before me, many women, many other people, when facing institutionalization, did not have the same luck I had. The professionals who look after them did not have the repertoire that would enable them to recognize what today we call the Autistic Spectrum Disorder.

Because our disability is invisible, one does not notice it in their first impression of us.





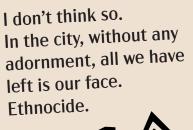
What in us is visible?

ECOLALIA

- Take off your mask so that I can see your Indian face! I saw no malice in these words.
 - What a pretty Indian!
- Take off your mask so that I can see your Indian face!
- Ah, she only looks like an Indian from her nose up. From the nose down she looks like something else.
- Take off your mask so that I can see your Indian face!

- Ah, but you must be of mixed race, right?

- Take off the mask so I can see your Indian face!





We are people with subtitles. People with disability.

What is the core of our autistic identity?



Is it our experience with capacitism? Or our unique way of communicating with the world?

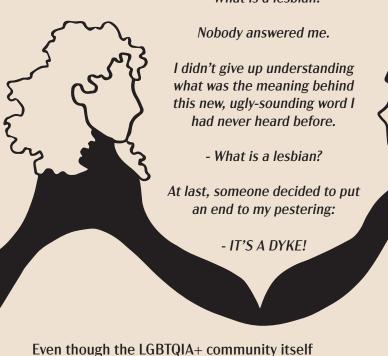
Had we not gone through the experience of capacitism, what would bind us as a community, what would give contours to our identity?

I believe the notion of identity serves a political purpose: a community wants to fight for its rights, wants to have the right to exist.

What is the minimum acceptable level of autonomy one could have?

I cannot understand whether there is in fact an autistic identity, or if this is an identity derived from our experience with capacitism. If capacitism did not exist, would there be such thing as an autistic identity?

It makes no sense to try to rank the degree of suffering that different disabilities can cause, because everyone who has a disability somehow suffers with capacitism. Still, there seems to be an interest in disqualifying invisible disabilities: if one condition is not recognized as a disability, it means it does not require accessibility, given the fact that it is the presence of a disability that makes accessibility necessary.



Even though the LGBTQIA+ community itself represents a break from an established pattern, autism certainly made it more difficult for me to exercise my sexuality. Only after the age of 24 was I able to relate to other people affectively and sexually, both due to a lack of opportunities and because I faced communication and sensory challenges.

before. I felt some embarrassment as I realized I was meant to become one of those women when I grew up.

I had heard

the word 'dyke'

Being out of the norm is tiring.

Disability is not perceived as natural, because it hinders the productive life that operates as the driving force of the world we live in, giving meaning to existence as a whole. In a society where life is centered around production, someone who does not produce (or who produces less) has no right to live. How can we contribute to a world that oppresses us, denying our existence? I am not fighting to find a space in this society. I am fighting to transform society from our point of view.

Disabled.

We need to build a world in which we are no longer disposable.

a little bit more about Carol



I was born in 1997, just three years after Asperger's Syndrome was included in the DSM-IV, in a city called Mairi-eté, nicknamed Belém do Pará by those who came later. I lived there only during my first year of life, then moved shortly after to Macapá, capital of the state of Amapá, where I would live until 2021, when I migrated to the southeast of Brazil. My mother was born in Abaetetuba, and my father was born in Furo da Cidade, municipality of Afuá, both located in the state of Pará. My parents moved to Belém to study nursing. Even though we grew up in the city, we kept our Amazonian roots alive.

My parents' studies allowed us to live a comfortable life. Though we didn't have any luxuries, we had access to good quality education and health care, and for this reason we had the opportunity to continue our studies in the southeast of the country. I am currently doing a master's degree in architecture.

Although the name of the people I originated from remains unknow to me, I self-declare as an indigenous person. Though we always knew we had indigenous origins, our family has been facing an ongoing process of ethnocide, an erasure of our history as native peoples. For this reason, I have been getting closer to indigenous collectives which, having gone through similar experiences, are now in the process of reclaiming their memory.

I was diagnosed with Autistic Spectrum Disorder in 2018, after four months staying in a semi-inpatient care mental health clinic, due to my depressive crises. Besides facing several difficulties before the autism had been identified, I also suffered from lack of acceptance for being a lesbian. Now, almost five years after the diagnosis, while receiving appropriated therapy and care, I feel more comfortable with who I am.



I have a lot of anger and whenever I look at it deeply I realize this is not only an anger related to the violence and inequality that run wild in this world. it is an anger addressed at myself an anger so introjected that it goes unnoticed just like this just like my invisible disability

at some point it reaches a limit it begins to struggle

I don't know where this anger lies, hibernating
but whenever it starts struggling
I can feel all over my head/body
an urge to blow everything up

anger is the fruit of all the messages
of devaluation
I have been hearing all my life
subliminal messages
that go unnoticed
just like this
just like my invisible
disability

being devalued makes us want to disappear: "if I feel so inadequate, there's no need for me to be in this world" it's been a long time since I understood that this inadequacy is not only mine it belongs to the world

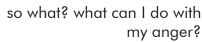
and still, I have so many doubts whether I will or will not be able to do this or that and such doubts affect from the most banal things to the major steps I need to take in order to live and to participate in this world

when I found out I was
autistic
I felt a great relief
but since then I have also been aware of
a great responsibility
the responsibility of no longer allowing autism
to go
unnoticed
of no longer forcing myself
to be and to do things
that slowly kill me
on the inside

the answer I receive to my attempt to take care of this structural condition which affects my existence as a whole is even more isolation but yes,
I am not the one isolating myself
it is the world that makes itself
inaccessible

while taking care of myself, once more I receive
yet another label
which only makes
the anger
increase

people don't even notice.
perhaps because the world
appears to have itself an
invisible
disability
one that makes it unable
to perceive and to be sensitive
with all its senses
and not only the sight.







Becoming collapse

I. About the invisible

Something has been happening in my body for eight years. Something that sneaks away from imaging scans, that doesn't show up in blood tests. Something that has been slowly taking hold... at first of my neck, then started coming down through my spine, finally claiming each of my body parts one by one, reaching every bone, every vertebra, every muscle fiber, every nerve, every tendon along its way.

I was following it, like an anatomist would, through the sensations that kept coming forth: tingling, pain, stiffness, more pain,

loss of movement, pinched nerves, paralysis, despair.

In every part there was a different tone of pain, with its own style and intensity, its own corresponding state

Sometimes I would turn into a vegetable, becoming still

sometimes I would become a reptile, crawling

sometimes I would grow into a mammal, yearning for someone's lap.

Only rarely I would remain biped

Curiously, my right side, crawling, props itself up over the left one. "One of my halves collapsed," I think. The other side, the one still healthy, ends up exhausted from having to carry the dying one. Sometimes I think that living like this is absurd. Other times, I come to the conclusion that living in whatever way is absurd, anyhow. So let it be.

The movement, in its turn, becomes delicate, slow, as if performed by a sick dancer*. Its collapse cannot be perceived from the outside. He keeps dancing, after all. Inside, the other that is also me

collapses slowly

and then glides throughout time, unfolding space, attempting to catch up

... slowly and carefully I return to the vertical axis (which, in fact, should we pay enough attention, we would recognize as a diagonal axis) and restart. Dancing.

II. Becoming Canary

Fibromyalgia is a name created to address a mysterious condition affecting mostly people with uterus, in a ratio of 9 to 1. Its causes remain still unknown. What we do know is that the nervous system at some point starts to function differently. Quite suddenly. As if it had lost the ability not to feel pain. In medical literature, the technical term is "central sensitization". It seems to affect organisms that are particularly sensitive to the toxicity of the Anthropocene*1. The spectrum of this toxicity is quite broad. It ranges from the contamination affecting the materiality of life (land, water, air, blood) to less palpable toxicities (affecting frequencies, vibrations, speed, states of mind).

The nervous system is an interface between body and mind, between inside and outside. This is not, therefore, a disease. This is a warning.

In the 19th century, canaries were kidnapped, put in cages and taken to coal mines, in order to serve as a warning to the miners, alerting them to the degree of air contamination during the excavations. While the male birds were trafficked around the world to cheer mankind with their sad songs, the female birds, when considered not useful for breeding, were recruited to the mines. Whenever they stopped singing, fainted, or simply died, the workers of the mine would know this was their sign to run away. From the moment the little bird fainted onwards, they had 20 spare minutes to escape.

It seems to me the metaphor could not be more accurate: these beings, hyper-sensitive to the toxicity of the world, were forcibly led to the excavations, to the subterranean depths of a world in ruins. But then, since we have already stopped singing, why hasn't the mine been abandoned yet? I wonder how much time we have left.

III. In Praise of Inability, or How to Inhabit Collapse

There seems to be no room in this world, or in this language, for an experience so close to that of ceasing to be. On principle, only death could embrace such a state. Paradoxically, though, this seems not to be a fatal condition. A problem then arises:

what can animate a collapsed organism? Though in Portuguese, the word 'animate' could be used to suggest a sense of euphoria or excitement, this is not the way we are employing it here: in this context, 'animate' refers to our very belonging to the universe of the living. To that which makes an organism vibrate. The only answer I could find emerges from sensations, more than from that which we call thought, or reason: what makes an organism in state of collapse vibrate is something entirely different. It is slowness... the keen perception of that which cannot be seen, that which can only felt, something that remains there... lurking in the background.

What animates this body is, therefore, a mysterious force, one that makes itself present in the emptiness, in the silence... with clarinet tunes in the backstage. It is the same thing that animates all the other beings in the world, after all. I believe the difference here is that the collapsing body, in other words, my body, throbbing in the present moment, is animated by connection, by porosity, rather than by its contours. Whenever the boundaries of the self are reinforced the way they are usually encouraged to be, I fall. While falling, I realize... .why the caged canaries sing*. Singing is everything we can do to slide away from that which imprisons us.

I enjoy this non-place, which allows me to observe from afar the frenetic pace of the productive bodies. Non-place as a space of its own, destined to not-being. A space which offers us a secret, almost unspeakable freedom, in face of a burnout society*, a market of souls, of zombies*with I don't know how many followers, whose tired look is made of thin air.

sustaining with grace the space of failure

continuously ceasing to be... in exile... in ruins.

what once appeared as tragedy becomes, little by little, a dis-concerting relief,

a poetic license coming from the world of the army of the uplifted*. Not belonging is liberating. I disappear, therefore, I can finally exist.

¹ While the Greek prefix "anthropo" means human, the suffix "ceno" refers to geological eras. The concept of the "anthropocene" was popularized by the Dutch chemist Paul Crutzen, who proposed it to designate what would be a new geological epoch characterized by the human impact on Earth.

Notes

sick dancer. Reference to the book The Sick Dancer, by Hijikata Tatsumi, one of the creators of butoh. In that book, there is an invitation to choreograph symptoms, to allow the horror to dance inside the body. Thus, the ruins of the self take on another meaning, bringing forth yet another sensation. In this twist, fragility becomes strength: to disappear is to exist.

anthropocene. why the caged canaries sing. Reference to Maya Angelou's book *I know why the caged birds sing*, which, in its turn, makes a reference to the poem *Sympathy* by Paul Laurence Dumbar, which narrates the pain of imprisonment. The pain of stunted wings, when freedom is at once so near and so far.

burnout society. This is the title of a book by the South Korean philosopher Byung-Chul Han, who points out to the way the growing social pressure to be productive does not limit itself to the sphere of work, but goes beyond to affect the vision we have of ourselves, therefore generating psychic illnesses typical of our time.

zombie. The origin of the word *zombie* goes back to the resistance of the Bakweri people, in Cameroon, against the advance of capitalism and the recruitment of its population to (under)paid work, by the end of the 19th century. The word was employed to denounce that, behind the fantasy of the fair exchange of labor for money, there was a soul being sold.

army of the uplifted. This is an expression by Virginia Woolf's expression, which appears in her essay *On Being III*, in this precious passage: "Directly the bed is called for, or, sunk deep among pillows in one chair, we raise our feet even an inch above the ground on another, we cease to be soldiers in the army of the upright; we become deserters. They march to battle. We float with the sticks on the stream; helter skelter with the dead leaves on the lawn, irresponsible and disinterested and able, perhaps for the first time for years, to look round, to look up – to look, for example, at the sky."

a little bit more about tao

I am a transmasculine being living with an invisible disability.

I was born in Brasilia, in 1984. My grandparents came from Goiania, in 1960, during a migrating wave which brought a lot of people to the region in order to build the country's new capital. I have a picture hanging on my wall showing my grandfather, a black man, standing in front of a shed, where he opened a modest little screw shop. As the store started growing, my mother's family managed to move from the outskirts of the Federal District a more central area, one of the parts of Brasilia which is usually referred to as "the wings of the plane", and there I was born. For this reason, I grew up in a very comfortable middle-class context. Since I was born white, one could say I had both material and racial privileges.

Even though I have been a boy from early childhood, I was considered a girl due to anatomical criteria. I lived like this, being perceived as a girl, until last year, when I finally couldn't stand it anymore. Now I am a rather hybrid, amphibious being. After spending half of my life underwater, I am now trying to recover the masculinity that has been expressing itself in me since I was a tadpole. I am happy to say that this deliciously corrupted, impure masculinity has not much to do with being a man.

I graduated in Anthropology at the University of Brasilia. It was there I turned into an activist, a feminist with strong anarchist tendencies. I was arrested in 2006, when I was involved in an occupation known as "Casa das Pombas". Soon after that, I went to Mexico, got a master's degree, and started working with feminicide and sexual violence. In 2011, I left the academy to commit myself entirely to activism related to feminist justice in Mexico City. In 2016, I received an invitation to take part in the construction of a popular feminist school in southern Mexico, in Oaxaca. In 2019, when the strong pain I had been feeling since 2014 started to affect my ability to function in the world, I returned to Brazil. Once back, I was diagnosed with fibromyalgia, and since then I have been living with this condition and relating to it on a daily basis.

Currently, I live close to the nature, in the outskirts of Brasilia, in the company of three exceptional canine individuals.

when I started to create this text about my existence and how's to be? somebody with an invisible disability. I've seen myself in many places when it comes to procrastination, postponement, frustration, there's a lot of stuff and all of them kinds connect so fast I can't notice. what is this supposed to be? everyone said now i don't know anymore i just can't see myself in a way that I supposed to see, to behave. always against the typical so tired they is low - hi bed how its going? so cool meet you here in São Paulo's domatour i'll say "yes" even rothing is clear could you just turn up the volume? i wish i could've made a song without lyrics to explain better how I'm feeling bout being deaf and ADHD. maybe this confusion can be something able to do it

a little bit more about **ber**



I was born in Montenegro, in the countryside of the state of Rio Grande do Sul, where I currently live. I have always been a **faggot** child, restless, artistic. Despite the social barriers related to heteronormativity, I have always expressed myself in creative ways.

I grew up in Capela, a town with 12 thousand inhabitants. I was born into a white, upper middle-class family in a rural, conservative environment. Things got a lot better once I was able to leave home and move to Porto Alegre to attend college, at the age of 18. There I found more freedom to express myself, to understand who I was. Having grown up in a not welcoming environment made me develop a lot of anxiety. It's been one year since I started to recognize myself as a non-binary person, and to claim this space. This has been a complex and laborious process, but it has been allowing me to discover new possibilities of belonging.

At school, I was considered a difficult child. Today, at 27, I know that I am a deaf person with ADHD [Attention Deficit Hyperactivity Disorder] and OCD [Obsessive Compulsive Disorder]. I have always been quite disorganized. I would not finish the tasks I started, and would often oscillate between excitement and discouragement... Besides, I was also facing gender issues. I was always asking myself: "My God, what kind of being is this?" I was constantly doing what I was not supposed to do, becoming fond of what I was not supposed to like.

It took me five 5 years to understand that using hearing aids would be beneficial to me. There is still a prevailing notion according to which "deafness" means "not hearing" at all. My hearing loss does not affect all the frequencies (high, medium, low) in the same way. Even when wearing hearing aids, I often don't understand what people are saying, even though I can hear their voices. It's been a year and a half since I started working more actively in music production, one of my lifetime passions. When I first put the hearing devices on, hearing new sounds I had never heard before, such as the sounds of the piano, of running water, of birds, was something extremely exciting, meaningful to me.

Unfortunately, the hearing aids help, but they do not solve everything. Inhabiting certain spaces is a complex, ongoing challenge, requiring a fragile balance. I am often perceived as uninterested when I am not.



my body could easily correspond to some of the aspects of the established standard.

"so white, so skinny, so cute, so quiet"
"are you a model?"
(there was a time when I wanted to be an actress, but...
a model? of what?)
no, I am not a model.

I could not understand why, when I was ten years old, I heard this question so often.

first, because whenever I looked at myself, I did not see the same thing other people saw.

second, because it is quite violent to project this kind of thing onto a child.

compulsory cisgenderism

patriarchal, racist standards of beauty "be the standard female figure, replicate the stereotype.. therefore the security of our system will be guaranteed."

no, I'm not a model.
but still, I could often pass
I walked through the world wearing clothes that didn't fit me
that corresponded to compulsory ideas about gender and sexuality
and went along with the open doors that a white skin guarantees
in a racist society.

however, perhaps because at school I never had enough money for the snacks I didn't get to be a "beautiful, discreet homemaker"

¹ This expression, which went viral in Internet memes, figured in the title of a report on the wife of Michel Temer, the vice president who ended up taking over the executive role of the Brazilian government after the former president Dilma Rousseff was impeached. This article, entitled 'Marcela Temer: beautiful, discreet homemaker' was published in 2016, the same year in which the questionable impeachment of Rousseff took place. During this period, Brazil

my inadequacy cried out

the autistic inadequacy offers me the ability of not conforming to anything... it gives me the ability to perceive things in a raw, honest, ethical way. at a given moment, the attempt to represent the roles which were imposed on me gave way to a series of questions and discoveries:

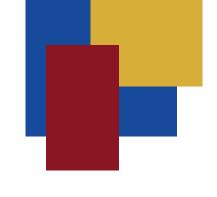
this binary separation doesn't make any sense..
I don't make sense within this binary, codified separation.
I won't allow my body be limited by such codes.. the existence can be so much more..

if the world is only able to see what fits inside an invented, replicated repertoire, then my existence needs to create another world.

a world sensitive enough to perceive us as diverse and unique at the same time. a realization that can be at once so simple and so powerful.

in such a world, diversity is not invisible. it doesn't even need to be visible: it can just be.

went through strong political conflicts, and the so-called moral agenda gained prominence amidst the ongoing narrative disputes.





there I was, taking a shower there I was, taking a shower in the men's restroom there I was, taking a shower in the men's restroom the restroom I started to use when I was 33 years old already

the showers were close to each other
there was a lot of water / some dirt / almost no furniture
there I was, taking off all my pieces of clothing
placing them one by one
on the other side
of the plastic curtain
taking care not to show myself from the waist down
trying to make sure no guy could look at my crotch
and realize
there was an organ missing

all the objects I carried with me were placed one by one on a rather wobbly shelf T-shirt, sock, underwear, japa mala, amulet I put my hearing aid in the pocket of my trousers at the very bottom of one of the pockets in the back of the of the trousers whose two legs I clumsily tried to fold over one another attempting to make sure my artificial ears would be somehow protected

but of course I couldn't manage to be careful enough during this awkward undressing

soon after the shower my chest hallucinated once I groped my pants and realized the pockets were empty

I scrabbled every aperture
I fumbled about in the floor, looked on the shelves
until I finally looked at the drain the drain oh no the drain oh no
my fingers weren't thin enough to pass through the gaps
so I had to use an iron instrument
to take off the metal lid
and only then, after groping around the gutter

I found my machine organ sinking on the dirty stream

once I recognized my sunken robot, everything started wheezing inside gasping for air after the washout my disconnected ears activated countless mechanical birds chirping inside

there was no agreement, no concordance no harmonic tonality possible

I FOUND. MY HEARING AID. FALLEN. IN THE DRAIN. I FOUND, MY HEARING AID. FALLEN. IN THE DRAIN.

what am I but an out-of-date cyborg an uncoordinated robot clumsy, awkward, incomplete I have teeth, machines and organs missing

electronic devices cannot survive in the water electronic device cannot survive dirty water so much shame and nonsense one day my lack of attention is bound to kill me

mirror mirror on the fall who in the world would be guilty of such a hazardous, nonsensical disaster?

the song announcing when the hearing aid is turned on and off keeps playing but its tunes are ironic this time the batteries are still being consumed but my artificial ears refuse to tell me anything

deprived of my prosthesis
I had to come closer to people's faces
in order to hear
the disagreement
I have no choice but to defy shame

now that the distance doesn't tell me anything

I seek the complicity of the lips the mouths that express themselves more openly the faces that allow me to come closer the jaws and tongues that articulate with emphasis because the lips whose movements are minimal remain unreadable, inaccessible to me

once the organs went missing, we discovered our multiple voices looking at our reflection in the shattered mirror some of us don't hear anything some of us are animals some of us are machines some of us are spirits some of us need to use the hands in order to touch the surface after all we never really learned to speak

metallic politeness hurts humor is alienating we rarely know for sure what everyone else is laughing at

you say something, I don't understand
I ask you what you said, I don't understand the answer
I ask you once more time, once again I don't understand
but in order to pretend I did
I improvise a speech developed from loose connections
of the few words I managed to steal from you
I embark on a digression
so as not to contort myself with shame

shame is always there polishing our armor

the metallic armor that creates a fence out of the muscles of the face forcing its contortions

no, I didn't hear when the pen fell to the floor I don't even know where the door of the house is

a little bit more about tom



I am a bit of a cyborg. Besides using hearing aids, I wear contact lenses, have seven titanium pins in my ankle, and have four dental implants in my mouth. I take testosterone injections every three months. My skin is white, and my hearing impairment is genetic. While my father, who was born in Inhambupe, a small town in the countryside of Bahia, started using hearing aids only after he was thirty, I, who was born in São Paulo in 1984 and grew up in a middle-class neighborhood, got my first pair of hearing aids when I was barely three years old. Both my parents were part of the first generation in their respective families to attend university - and though they faced economic hardships during their childhood, during adulthood they achieved a fairly stable financial situation, working as teachers. My mother grew up in Casa Verde, in the northern part of São Paulo. She is the daughter of a Portuguese couple who arrived in Brazil in the beginning of the 20th century, coming from Madeira Island.

My relationship with my hearing loss went through a quite a few twists and turns. Only around the age of twenty did I realize that I did lip-reading. Besides lips, I would often read pages: I have been a compulsive reader both during my childhood and adolescence. Years later, I graduated in philosophy and ended up becoming a poet. I do freelance jobs for a children's books publisher to survive. Voice and silence cut through everything I have ever done—and though I did quite a lot of performance art, during my gender transition, I shunned away from doing anything in public for a few years.

It has not long since I finally discovered what does it really mean to feel comfortable in one's own body. It took me a while to be able to figure out where my discomfort came from: it has only been nine years since I started recognizing myself as a transman. Being pansexual, someone who feels desire for people who look very different from one another, for a long time I felt somewhat alien.

"IF | DIDN'T DEFINE MYSELF FOR MYSELF: | WOULD BE

CRUNCHED INTO OTHER PEOPLE'S FANTASIES

FOR ME AND EATEN ALIVE: AUDRE LORDE

One day I didn't pass through the bus turnstile.

At that moment, on my way to the university, I didn't reflect on the way mobility can be used as a controlling tool

nor did I realize that accessibility has a potential to tear apart

the white, heteropatriarchal, ableist norm!...

SPEAK. NO SA

Depression
Hypothyroidism
Social phobia

all of them are chronic conditions, and the clock has never been ticking in my favor

... I simply introjected the mockery.

A black, fat girl coming from the outskirts whose sexuality is dissident should not be transiting certain spaces. For a long time, I did believe it.

Now I believe it is possible for us to collectively build

a society where the needs of people with functional diversities are a priority, as well as our intersectional existences.

a little bit more about natana



I was raised in Baixada Fluminense, in Rio de Janeiro. I come from a favela in São João de Meriti. I have two brothers. My mother comes from Baixada, and my father, from Campos. Both of them now live in the countryside. They decided to live a more peaceful life, leaving behind the violence that was present in the context in which we lived.

I entered college when I was 17 years old. I graduated in History and studied Literature for a few years. Even before that, I was already doing community work as a popular educator in Caxias, another city in Rio de Janeiro, teaching children to read and write. I became closely involved with social activism and black movements. Going through these experiences helped me understand to what extent my life at the time has been affected by racial issues, which allowed me to be aware of who I was in that context. All this would become part of my life trajectory.

Coming from a matriarchal family, I identify with the feminine in many ways. Though I am a daughter of Oxum, it's been a few years since I no longer recognize myself as a woman. I am still trying to find a comfortable, unique way to define myself.

As a teenager, I was diagnosed with depression. Only recently did I discover that I suffered from social phobia, a condition that has worsened due to the pandemic. My behavior was affected by the trauma produced by experiences involving fatphobia, racism, and bullying, as well as the sexual violence I experienced as a child. The attempts to perform according to compulsory gender and sexuality norms made me fall ill.

I am a singer songwriter. My music and my spirituality reconnect me with myself. Besides helping me to live better, they allow me to find appropriate care. I still often don't feel good around people, but I have discovered that, whenever I get to define myself with my own impressions, to see myself through my own lenses, I feel better. Currently, this is all that matters.



my genderless body started to hurt. though it already was transiting outside the fences of the normality standards, I still (thought) I had that so called ability suddenly my body started hurting the inflammation was coming, the stiffness was sticking... still, my steps continued to be guided by the rhythm of that so called ability

it's not that it had never hurt before, but this time something kept insisting and persisting. there is something wrong some of the systems is facing sickness autoimmune disease

my body is being attacked by the very cells that should protect it self sabotage
I wonder if, after not wanting to exist for so long my body has decided to attack itself?
it turns out that this is not a fatal attack...
the existence insists and persists.

perhaps the excess of action became the last resource of the protective system, a warning sign: "hey, you there: this so call ability is weighing you down, isn't it? here we are, to let you know that things can be different, and also that, if you insist on forgetting, we will offer you pain as a gift".

systemic inflammation.
it goes around: spine, hip, elbow,
thorax, hand, knee, ankle, heels.
it reaches the intestine, the skin, the
eyes.
the whole head/body balance is
affected.

and what about that so-called ability?
the one carrying the weight of productivity standards
ah! actually, it has never been so present,
after all, sensory hypersensitivity
has always been here
hanging around
(though everyone would say it was fussiness)

there is something wrong - or perhaps I am the wrong one? sick - physically disabled - mentally invisible

to what extent can body and mind be separated?

"you have a chronic illness" it is incurable, but treatable "you can lead a normal life. I have patients who run marathons."

and therefore I, who tend to understand what is said to me quite literally, went running, and though it was not a marathon, it was enough to make the pain insist and persist

what can one expect when one knows that one will have to deal with an illness for a lifetime? what kind of normal life is this?

I cannot do the same things any longer
I cannot eat the same things any longer
I no longer meet people the way I used to
and it is not that the pain paralyzes me: strange as it seems, the pain asks me to move.
but the movements it allows me to do
do not correspond to the rhythm of the so-called ability.
they are not the movements of a strong, agile, resistant body

here I am, standing still bipedal but feeling chronic pain being offered a seat is not always the kind of access I need.

this condition - confusion - attempts to remind me that another timing is necessary, that here one should to move little by little. the potency circulating here is of a different kind it is subtle micromovement

can you see? can you see my limitation? can you see your limitation?

what is invisible disability diversity

a little bit more about **iau**



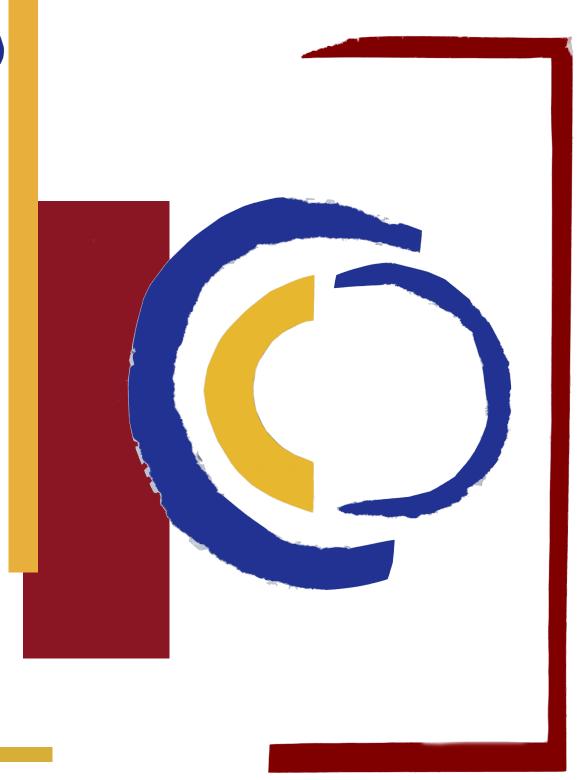
My family comes from the states of Bahia, Paraíba, and Pernambuco, in the Northeast part of Brazil, but my parents later migrated to the Southeast of the country. I was born in Rio de Janeiro, in 1985. I am a white person who grew up in an unstructured family environment, in a lower middle-class context. Even though I had good educational opportunities, because I was constantly interacting with children who had more money than me, I ended up developing a feeling of inferiority. Despite the troubled context around me, I think my early childhood, before puberty, was the happiest time of my life. I felt more freedom back then.

During my teenage years, because of social pressures to follow normative standards concerning gender and sexuality, I gradually stopped acting as the little hybrid creature I had been until then, who sometimes appeared to be "young lady", other times looked like a little lad. From the age of 26 onwards, I found a way to recover some of this childish freedom: I now recognize myself as a transgender person, neither identifying as a woman, nor as a man. I don't understand gender as something innately expressed. Nor am I able to label my sexuality. Being part of the LGBTIA+ community is a source of great joy!

I started working when I was 16 years old, and my professional and financial life has been unstable ever since. Because art has always been a refuge for me, I explored this field of study during both my bachelor and master's degrees. In the last years, I completed a PhD in Clinical Psychology.

When I was 35 years old, during the same year in which I was diagnosed with spondyloarthritis, I discovered I was autistic. Throughout my life, my characteristics related to autism has been mostly interpreted as fussiness, trivialized by almost everyone, including myself. I did not have access to proper care.

In my experience, my invisible disability and my gender and sexuality diversity are constantly intertwined: this is where my motivation to create this project came from. I am not what I appear to be, and I do not always appear to be what I am.



glossary

Intersectionality: it's a social study approach and a social practice that takes into account the interaction between different identity markers. Each person can be socially identified in multiple ways. and these social identities do not affect his or her experience in isolation: they are constantly intersecting and interacting with the context around them. Intersectionality helps us understand that injustices, oppressions, and inequalities occur in multidimensional ways. In this booklet, we will be addressing intersections between disability, gender, and sexuality, as well as observing how these experiences intersect with other identity markers, such as race, class, age, and geolocation.

Language: for us, the term language encompasses all forms of expression, and cannot be restricted to the verbalized, intelligible word. Language is not simply an act to be performed: it is rather the expression of the existence of every living being. The verbalized word is only one of the possible forms of language.

Transgender/trans: The word "transgender" is an adjective referring to people whose gender identity is not the same as the gender they were assigned with at birth. The term encompasses a range of different identities, among which we can mention: transsexual women, transsexual men, non-binary people. The word can also be employed to refer to issues related to this population, as, for example, when we refer to the "transgender movement", with its ac-

tivism and its struggle for their rights. The word "trans", in turn, can be used as an informal abbreviation of the same term. As a prefix, it originates from Latin, and means "across", "beyond", "through"; it suggests crossing, displacement, change from one condition to another.

Spectrum: we use the word spectrum to emphasize that experiences, in general, can express themselves in a wide, varied way, and can change shape and interact with each other. Throughout this booklet, we depart from the point of view that experiences linked to disability, gender, and sexuality all need to be understood according to the the range of their spectrum, they should not be understood as static conditions. These experiences are unique and present characteristic modulations. We can recognize a spectrum in different ways: besides manifesting itself in the great diversity of possible experiences and conditions that exist in different societies, it also contemplates the variations that can occur throughout the life of the same individual.

Equity the central starting point of this concept is to observe the different experiences of people taking part of the same society in order to recognize elements which will allow us to organize and structure public endeavors to make spaces of circulation and interaction more accessible, so as to make social relations fairer. When the coexistence is based on equity, all bodies/minds are taken into account with their different potentialities and limitations, having access to a fair measure of

whatever they need to thrive, enjoying life in all its spheres. Equity is directly related to justice; it is not synonymous with equality.

Accessibility: it is a concept linked to disability studies. It addresses the need for several instances of social interaction to become more accessible to a given portion of the population. A society designed only for people without disabilities, oriented by a generic model of what they would supposedly recognize as an able subject, ends up creating barriers for individuals who do not match this model. We find examples of such barriers in several fields: in architecture and urban planning, in access to education, in health and leisure services, and even in social attitudes and behavior. Just like other terms associated with the context of disability, the word "accessibility" can also be employed to refer to other forms of exclusion - it can be used, for instance, to refer to the obstacles that prevent transgender people from accessing public toilets.

Ableism: a term coined to name specifically the oppression and discrimination against people with disabilities. It should be understood, however, a system of oppression that is articulated transversally to others, such as patriarchy, colonialism, racism, speciesism, and ageism. The ableist point of view establishes a hierarchy among people, operating through the depreciation and exclusion of those who do not correspond to the standard model of a typical subject, therefore establishing a leveling that associates the value of a person to his or her ability to produce. The ableism can appear either in an explicit form, appearing directly in the vocabulary used in interactions and speeches, but also in a more a subjective,

veiled form, permeating social and interpersonal behavior.

LGBTIA+: acronym that designates different expressions of gender and sexual diversity. Its letters correspond to: lesbian, gay, bisexual, transsexual/transgender, queer, intersex, asexual. The symbol + is used to refer to other gender identities and sexual orientations that are not directly mentioned.

Cisgender/cis: the word "cisgender" was created to refer to people who identify with the gender they were assigned with at birth. The prefix "cis", which is often used as an abbreviation of the previous term, originated from Latin, and means "on the side of", as opposed to "trans", which means "on the other side of".

Transphobia: term used to refer to the discrimination against transgender people. Transphobia can manifest itself both in explicitly violent acts and in a more veiled way, through the non-recognition of transgender identities as being part of the social diversity.

Sensibility: a greater or lesser willingness to perceive the other so as to notice characteristics that might not be necessarily visible or evident. We propose that the modulations of sensibility should become a criterion for the organization of social structures and interactions, allowing us to establish relationships based on more subtle perceptions. The word "sensibility" reports to the notion of "sensations", to the way things affect us, including a wide range that encompasses physical sensations, emerging from the sensory dimension, the five senses, but also emotional, psychic sensations. Sensibility is modulable. It doesn't remain static not even in the same

individual, varying considerably from one being to another.

Echolalia: medical term referring to a common characteristic in individuals with Autistic Spectrum Disorder, marked by the repetition of words and sounds. It is a form of sensory self-stimulation (stim) that allows for emotional self-regulation. It also refers to the habit of fixing one's thoughts on words, phrases or ideas, for hours on a loop. In these cases, echolalia might have either the function of processing a particular piece of information or reflects one's difficulty to detach themselves from a fact, event or sensory stimulus.

Heterodeclaration: The act by which individuals or groups either name or qualify the identity of other individuals or groups. The opposite of self-declaration.

Ethnocide: Strategy or process of erasing the capacity of certain groups to differentiate themselves from others. Its effect is the impossibility of remaining, perpetuating, and transmitting one's customs, languages, cultural practices, and to affirm one's ethnicity. It has been one of the factors contributing to the genocide of the indigenous population of Abya Yala (America).

Dyke: a term previously used to refer pejoratively to women who relate sexually and affectively with other women, which was later reappropriated by the lesbian community. As an identity, it cannot be restricted to sexuality: it also suggests a subversion of gender, since some dykes do not even consider themselves to be women. Faggot: a word that appeared as an insult directed at homosexual or effeminated men. Like other pejorative terms directed at the LGBTQIA+ population, over time the word "faggot" started to be used within the community in a familiar, affectionate, humorous and friendly way.

Heteronormativity: as the very construction structure of the word suggests, it is a term created to describe the way in which heterosexuality is constructed as a social norm. It refers to a society structured from the perspective that only heterosexual relationships can be considered correct and be accepted socially. It is a concept created and employed to expose and criticize social practices that attempt to impose their normative standards on the sexual orientation and expression of individuals.

Fatphobia: a term used to refer to the prejudice directed against fat people. Fatphobia is a stance that can be identified in current social practices that repeateadly disqualify the fat body, both aesthetically, by excluding it from its beauty norms, and in the functional sense, relating it to lazyness, a characteristic that is very estigmatized in a society whose main focus is the production of capital.

references

Reference materials, and related content:

- About Hidden Disabilities. Website Hidden Disability Symbol Canada (HDSC), s/d.
- A diferença invisível [The invisible difference], by Julie Danchez and Mademoiselle Caroline. São Paulo: Nemo, 2021.
- Antra Associação Nacional de Travestis e Transexuais, website of the National brazilian association of travestis and transexuals.
- A nova CID 11 no contexto nacional [The new CID 11 in the national context]. Transvida 2022 – special edition "Visibilidade trans", organized by Felipe Martins.
- A resistência dos vagalumes [The resistence of the fireflies], by Cristina Judar e Alexandre Rabelo (org.). São Paulo: Editora Nós, 2019.
- Changing the Framework: Disability Justice by Mia Mingus. Author's blog2011.
- Crip Camp. Directed by James Lebrecht and Nicole Newnham. Produced by James Lebrecht, Nicole Newnham and Sara Bolder. Streaming production: Netflix. United States of America, 2020.
- Deficiência em questão: para uma crise da normalidade [Disability in question: towards a crises of normality] by Marcia de Moraes, Bruno Sena Martins, Fernando Fontes and Luiza Teles Mascarenhas(org.). Rio de Janeiro: Nau, 2017.
- <u>Deficiências invisíveis: o que são e o que você precisa saber sobre elas.</u> [Invisible
 Disabilities: What They Are and What You Need to Know About Them] Website Inova
 Social, 2018.
- Diretrizes para o cuidado das pessoas com doenças crônicas nas redes de atenção à saúde nas linhas de cuidado prioritárias. [Guidelines for the care of people with chronic diseases in health care networks in priority care]. Brazilian Minister of Health, Helth Attention Secretary, Departament of Basic Attention. Brasília: Ministério da Saúde, 2013.
- FONATRANS NGO
- Hidden Disabilities Sunflower
- História do Movimento Político das Pessoas com Deficiência no Brasil. [History of the Political Movement of People with Disabilities in Brazil] Documentary produced in 2010 by the National Secretary for Promotion of the Rights of People with Disability. Research realized by CPDOC/FGV.
- Invisible Disabilities Association US
- Invisible Disabilities: List and General Information. Website Disabled World, 2022.
- Invisible Diversity: A Story of Undiagnosed Autism. Carrie Beckwith-Fellows, TEDxVilnius.

- Intransitivo um documentário sobre narrativas trans. [Intransitive a documentary about trans narratives]. Directed by Gabz 404, Gustavo Deon, Lau Graef e Luka Machado, 2021.
- <u>Introvertendo um podcast onde autistas conversam.</u> [Introverting a podcast where autistic people talk]
- Ivan Baron brazilian influencer addressing the topic of inclusion
- LBI [Brazilian Law of Inclusion of people with disability]: Law number 13.146, written in July 6 2015, establishing Lei brasileira de inclusão da pessoa com deficiência (Estatuto da pessoa com deficiência) / Brazilian Chamber of Representatives. Brasília: Câmara dos Deputados, Edições Câmara, 2015.
- Lei de Cotas: Quais deficiências se enquadram na Lei de Cotas. [Quotas Act: Which disabilities fall under the Quotas Act]. Website PCD+, 2020.
- Mortes e violências contra LGBTI+ no Brasil: Dossiê 2021 by Acontece Arte e Política LGBTI+; ANTRA (National Association of Travestis and Transexuals); ABGLT ((Brasilian Association of Lesbian, Gays, Bissexuals, Tranvestites, Transexuails and Intersex). – Florianópolis, SC: Acontece, ANTRA, ABGLT, 2022.
- Mortes violentas de LGBT+ Brasil [Violent deaths of LGBT+ in Brazil], by Observatório do Grupo Gay da Bahia, 2022. Instagram of Grupo Gay da Bahia (GGB), 2023.
- <u>Notas Neuroatípicas</u> [Neurotipical notes] by Luciana Mendonça, TEA / TDAH Creator of digital content.
- O cuidado das condições crônicas na atenção primária à saúde: o imperativo da consolidação da estratégia da saúde da família. [Chronic conditions in primary health care: the imperative of consolidating the family health strategy], by Eugênio Vilaça Mendes. Brasília: Organização Pan-Americana da Saúde, 2012.
- Opinião Capacitismo. [Opinion Ableism]. Journalistic TV broadcast by TV Cultura.
- O Plano de Ações Estratégicas para o Enfrentamento das Doenças Crônicas e Agravos Não Transmissíveis 2021-2030. [The Strategic Action Plan for Confronting Chronic Diseases and Non-Communicable Diseases 2021-2030]. Ministery of Health, Secretary of Health Vigilance, Department of Health Analysis and Prevention of Non-Transmissible diseases. Brasília: Ministério da Saúde, 2021.
- O normal e o patológico, by Georges Canguilhem. Rio de Janeiro: Forense Universitária, 2014.
- O que é a deficiência [What is disability], by Debora Diniz. São Paulo: Brasiliense, 2017.
- O que é a neurodiversidade? [What is neurodiversity?], by Tiago Abreu. Goiânia: Cânone Editorial, 2021.
- O que podemos aprender com as deficiências não visíveis [What we can learn from invisible disabilities], by Karolina Cordeiro. Website of the NGO Nossa Causa, 2016.

- Orientações sobre identidade de gênero: conceitos e termos [Gender identity guidelines: concepts and terms], by Jaqueline Gomes de Jesus. Brasília, 2012.
- Post about the origin of the words faggot, queer and dyke. Facebook Midia Ninja.
- Qual o seu sonho? [What is your dream?], by Cynthia Macedo. Website Amigos Múltiplos da Esclerose, 2016.
- Sick Woman Theory by Johanna Hedva. Website Tropical Cream, 2022.
- Skin, Tooth, and Bone The Basis of Movement is Our People: A Disability Justice Primer by the collective Sins Invalid. Printed in USA, 2016.
- Sins Invalid a disability justice performance project
- Unrest. Directed by Jennifer Brea. Produced by Patricia Gillespie e Alysa Nahmias.
 Streaming distribution: Netflix. United States of America, 2022.
- <u>Vale PCD</u> intersectional project on disability and diversity of gender and sexuality
- Violência contra pessoas com deficiência: o que dizem os dados da saúde pública? [Violence Against Persons with Disabilities: What Public Health Data Says] Ministry of Economy, Institute of Applied Economic Research, Directorate of Studies and Policies of the State, Institutions and Democracy. Brasília: Ministério da Economia, 2021.
- Vinte e quatro notas de viadagem [Twenty-four faggot notes], by Leandro Soares da Silva.
 Revista Periódicus, 2nd edition, November 2014 April 2015.
- Visualizando o corpo: teorias ocidentais e sujeitos africanos [Visualizing the Body Western Theories and African Subjects] by Oyèrónké Oyèwùmí. In: A invenção das mulheres: construindo um sentido africano para os discursos ocidentais de gênero. [The Invention of Women: Making an African Sense of Western Gender Discourses] Rio de Janeiro: Bazar do Tempo, 2021.

Reference in Tao Itacaramby's text

- Sociedade do cansaço [Burnout society], by Byung-Chul Han. Petrópolis, RJ: Vozes, 2015
- Canários: 5 fragmentos, [Canary: 5 fragments], by Bábara Marcel, Andreas Doepke and Tom Nóbrega. In: "Cadernos Desilha 3: exercícios de paisagem. Rio de Janeiro: PPGAV EBA UFRJ, Editora Circuito, 2021.
- De la necropolítica neoliberal a la empatía radical: Violencia discreta, cuerpos excluídos [From neoliberal necropolitics to radical empathy: Discreet violence, excluded bodies], by Clara Valverde Gefaell. Icaria editorial; 1st edition, 2015
- Hijikata Tatsumi: Pensar um corpo esgotado [Hijikata Tatsumi: Thinking an Exhausted Body] by Kuniichi Uno. São Paulo: n-1 edições, 2018.
- Eu sei por que o pássaro canta na gaiola [I know why caged birds sing], by Maya Angelou.
 São Paulo: Astral Cultural, 2018.
- Ni zombis, ni Robots: la libertad y sus colmillos [Neither zombies nor Robots: Freedom and its fangs], by Tao Itacaramby.
- Sobre estar doente [About being ill], by Virginia Woolf. São Paulo: Editora Nós, 2021.

