Experiences and Actions of Mothers of Children with Disabilities in Peripheral Brazil: Microactivism as Resistance to Shrunken Affordances

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Abstract

This thesis aims to explore how the experiences and actions of mothers of children with disabilities in peripheral communities in Brazil challenge the understandings of disability activism. Using a Critical Disability Studies (CDS) framework that combines political/relational conceptions of disability, care and activism with an intersectional lens to expand Arseli Dokumaci's *microactivist affordances* (2019, 2020), the study examines how these mothers navigate and respond to intersecting systems of oppression and state neglect within the periphery. The thesis draws on rich qualitative data collected through creative, participatory methods in collaboration with civil society partners, including mothers of children with disabilities and mothers with disabilities in the project design.

An abductive thematic analysis reveals that existing disability activism models, rooted in Western, binary (disabled/non-disabled) frameworks, fail to account for the lived realities of mothers of children with disabilities in the periphery. These mothers experience disability not only through their children's embodied experiences but also through contexts of "shrunken affordances" - systemic limitations shaped by intersecting systems of disability, gender, race, social class and geographic marginalisation. The thesis builds on the works of Dokumaci (2019, 2020, 2023) to develop the concept of *microactivism* to describe mothers' everyday actions of resistance, reimagination, and struggle at the individual and community level, and (*macro)activism* to describe systems-level advocacy rooted in and sustained by *microactivist networks* of mothers. By conceptualising activism as a continuum shaped by relational, collective, and context-specific experiences, this research offers new insights into how mothers of children with disabilities in marginalised settings redefine what it means to act politically within the disability space.

Key words: disability, activism, mothers, children with disabilities, Brazil

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List of Acronyms

BPC – Benefício Prestação Continuada [EN: Continuous Benefit Payment] - the main disability welfare benefit.
CDS – Critical Disability Studies
CRPD – The United Nations Convention on the Rights of Persons with Disabilities
CEDAW – The United Nations Convention on the Elimination of Discrimination Against Women
SUS - Sistema Único de Saúde [EN: The Unified Health System]
SUAS – Sistema Único de Assistência Social [EN: The Unified Social Assistance System]
UN – The United Nations
UPIAS – Union of the Physically Impaired Against Segregation

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Declaration

I declare that this thesis is a presentation of original work and I am the sole author. This work has not previously been presented for an award at this, or any other, University. All sources are acknowledged as References.

Introduction

Origins

The Zika epidemic, which emerged in Brazil in 2015, disproportionately affected Black women, particularly in the northeastern states where Black populations are concentrated (Lower et al., 2018; Vissoci et al., 2018). An estimated 14,558 babies were born with Congenital Zika Syndrome (CZS)[1] between 2015 and 2017, though many struggled to receive a confirmed diagnosis. Zika's spread was linked to conditions of poverty, poor sanitation, limited contraception, malnutrition, and insecure housing, more prevalent in Black communities due to structural racism (Barbeito-Andrés et al., 2020; Boing et al., 2021). Ministry of Health data showed that 84.3% of CZS mothers were Black, most of them young and single (Center for Reproductive Rights, 2018; Marinho et al., 2016). These figures highlight the racialised and gendered aspects of the epidemic and the broader structural oppressions it exposed.

In the years following, families affected by CZS faced chronic state neglect, limited access to services, and mounting financial burdens (UNDP, 2017; Honeycutt et al., 2004). Caregivers, particularly mothers, report poorer mental health, including higher levels of stress and depression (Kuper et al., 2018, 2019). In response, mothers formed Zika networks starting in 2016, developing a collective identity as 'micro mothers' rooted in care knowledge and mutual support (Vale, Alves & Carvalho, 2020). Over time, their role expanded into advocacy, negotiating for access to public services and rights (Moreira, 2018), embodying what Panitch (2008) calls, mothers becoming 'accidental activists'.

This thesis grew as part of an ongoing collaborative project with civil society organisations in Brazil that evolved from previous research, which responded to Zika and some of the related issues outlined. One of these projects, 'Afterlives of Zika', was a collaborative project between the University of York and Fundação Oswaldo Cruz (Fiocruz) in Brazil, looking at the experiences of mothers and children with Congenital Zika Syndrome (CZS) who, in the aftermath of the Zika epidemic, had been subjects of an international research and media sensation which subsequently faded (University of York, 2018). While working at the University of York in 2018, I met two mother leaders, Germana Soares and Vanessa Aguiar, who had been involved in political campaigning since their children were born to secure their rights to social protection, healthcare and education. Whilst the contexts were very different, I recognised the challenges they were facing as ones that my own and many other families were facing in the UK, which left a lasting impression. Having completed my master's thesis a year earlier looking at the political mobilisation of disability movements in

[1] CZS is a neurological condition associated with lifelong and multiple disabilities in children born to infected mothers.

Bangkok to fight against public transport inaccessibility, I was interested in better understanding how mothers politically organised and enacted their activism, despite being 'outside' of, and being seen as separate to, the disability rights movement, and despite the extreme difficulties they and other families faced in providing for their children's basic needs.

During this visit from members of Fiocruz along with the mothers, I was invited by members of the research team, including my current supervisor, João Nunes, to apply for a PhD programme to focus on the experiences of the families impacted by the Zika epidemic from a disability rights approach. The original version of this thesis did just that. However, impacts from the Covid-19 pandemic and its implications both for these families and for the practicalities of my PhD, along with the influence of another research and advocacy project (detailed in the methodology chapter), meant that the project evolved into its current form, that takes a broader disability focus but retains a focus on mothers of children with disabilities in peripheral contexts and their networks.

The study design was therefore influenced by these collaborations and previous/parallel projects, which led to the development of the non-academic objectives of the project with civil society project partners, as presented in subsection D, below. The collaboration with civil society also informed the community-based action research, ethnography, interdisciplinary, and participatory methods that will be explained further in Chapter Four. Additionally, this approach was influenced by the work of Paulo Freire (1970) and underpinned by a Critical Disability Studies theoretical framework that emphasises the importance of engaging communities in the research process. Beyond this thesis, the other project outputs that satisfied the non-academic objectives of the project include a project report (included in Appendix J) designed for policy advocacy by the partners, and contributions to several alternative advocacy reports using the United Nations (UN) human rights mechanisms.

Situating the project

The lack of public policies and access to care and support for people with disabilities in Brazil disproportionately impacts low-income, Black and peripheral communities, and places the responsibility of care and support within the family. Although care work forms a significant part of the formal domestic work market, the majority of care work in Brazil continues to be done informally by family members, (94.1%), majority women (72.1%) and with only a tiny minority being paid for this work (9.2%) (Giacomin, Duarte, Camarano, Nunes, & Fernandes, 2018). However worrying these numbers are, they are likely to be underestimated owing to the invisibilisation and depoliticisation of care work as a private, family matter. In the case of family care for children with disabilities, Brazil's patriarchal culture would appear to have

a significant influence. Whilst reliable data is not available, some research suggests that 78% of fathers of children with disabilities or rare diseases abandon their families (Câmara dos Deputados, 2022), whilst others put the figure more towards 95% (Minority Rights Group et al., 2022). This leaves mothers full responsibility for care, in what Williamson et al. (2023) call the chronification of gendered homemaking that leads to debilitation and isolation. Despite being portrayed as either neutral or a 'natural' part of women's work, care work in Brazil is gendered, racialised and disabled.

A central issue is the lack of progressive public policies on care to provide people with disabilities and their families with choice and adequate support. Beyond the links to gendered care already outlined, this has other profound implications for the violation of the rights of people with disabilities. For example, dependence on carers and social isolation are linked to the high rates of domestic violence that disproportionately impact women and girls with disabilities (de Mello & Nuernberg, 2012; IPEA, 2024). Furthermore, a policy landscape that places responsibility for care and support entirely on the family can also be linked to high rates of institutionalisation of people with disabilities in Brazil, many of whom 'stay until they die' in conditions that violate their fundamental human rights and dignity (Human Rights Watch, 2018; Rizzini & Almeida, 2011). Whilst it is beyond the scope of this study to investigate these related issues further, it foregrounds their relevance to understanding how interrelated structural inequalities rooted in race, gender, class and disability intersect with Brazil's care landscape. As such, the normalisation of unpaid, gendered and racialised care within families sets the context for this research. I begin by asking, how far do existing social movements and theoretical frameworks acknowledge and respond to the complex layering of these social justice issues?

The research problem

Disability Studies has developed as an essential field of research over the past few decades, closely linked to the development of national and international disability rights movements. More recently, the influence of Critical Race Theory, postcolonial, decolonial, queer and feminist theories has led to the development of a critical arm to the field, Critical Disability Studies (Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019). This influence has led to an increased engagement with sociocultural and historical contexts surrounding disability experiences, including a critical engagement with the intertwined and intersecting oppressions that impact people's everyday lives. It has further led to the development of poststructural approaches to explain the disability experience that reject the biomedical model of disability but also question the hegemony of western, social model and binary approaches to disability (Ben-Moshe et al., 2016; Daniel Goodley & Runswick-Cole, 2016; Green, Darling, & Wilbers, 2013; Kafer, 2013; Schalk, 2017). As a result, there has been increasing attention to other social factors surrounding disability, such as race, social class,

and gender, and increasing attention paid to disability experiences in the Global South. These racialised, indigenous and queer contexts have been historically excluded from the field. I will further explore these ideas in the theoretical framework presented in Chapter Two.

In both Disability Studies and Critical Disability Studies, there is a vast body of research that investigates the role of parents' movements in disability activism, pointing to the tensions between parents and disability movements led by activists with disabilities, and parents' organisations, which consequently sit on the fringes of mainstream disability activism. However, the majority of this research is set in Western countries like Canada (Panitch, 2008), the UK (Dumbleton, 2013; Langan, 2011; Ryan & Runswick-Cole, 2009; Walmsley, Tilley, Dumbleton, & Bardsley, 2017; Crow & Merchant, 2019; McLaughlin et al., 2008), New Zealand (Morrison et al, 2022), Sweden (Bertilsdotter Rosqvist et al. 2015) and the US (Carey, 2009; Carey, Block, & Scotch, 2019; Groce, 1996; Naples, 2013; Wright and Taylor, 2014; Orsini & Smith, 2010), which fits into new social movement theory focussing on middle class organising. Similarly, most research in Brazil has focused on the activism of middle-class parents (Block & Cavalcante, 2014; Brégain, 2013), analysing approaches to activism that are likely to differ from those in peripheral contexts.

The research problem to be addressed in this thesis, therefore, centres on how disability activism undertaken by mothers in peripheral contexts in Brazil intersects with gendered and racialised experiences, as well as their actions in response to those experiences. As will be demonstrated in the following chapter, the existing literature neglects the intersection of disability oppression and gender, particularly within the context of familial care policies, effectively depoliticising both the experiences of disability and the activism associated with care and access to services for children with disabilities. Second, this literature overlooks the experiences of people with disabilities and their families in peripheral contexts, where intersecting systems of oppression shape their lives, and where access to formal spaces like mainstream disability organising may be limited or non-existent. Where there is research on experiences of mothers of children with disabilities in the global south and non-majority or mainstream contexts, little attention is paid to the actions of mothers in resisting the difficulties they face.

Despite the work and approaches to advocacy by informal community networks that may not be recognised as 'disability activism' and therefore not a part of the mainstream disability rights or parents' movements, current Disability Studies literature lacks detailed studies of the contributions of mothers and mothers' networks that blur the boundaries between carer/cared for. Likewise, it fails to adequately address or explain discrimination based on disability, gender, race or social class and question what counts as disability activism in contexts where multiple systems of oppression are at play - for example, when networks provide mutual support, informal care or knowledge exchange as a form of

resistance to structures of oppression, through community-based survival strategies that do not rely on state structures (Piepzna-Samarasinha, 2018). Addressing this gap is crucial to furthering thinking around conceptualisations of disability and resistance that take a more holistic, culturally and historically situated approach - one that moves away from universal models of disability, which fall short of explaining the experiences of those in peripheral and global south contexts.

This thesis, therefore, aims to explore how disability activism is enacted within these settings to address the link between disability, race and gender discrimination that culminates in the experiences of people with disabilities and their caregivers, who are primarily women from marginalised and racialised communities. Offering an overview of all informal community networks across Brazil is beyond the scope of this study. However, by providing case studies of networks across four states, it is hoped that this thesis will contribute to an understanding of how actions of individuals and networks can contribute to current understandings of disability activism. This research takes a multiple case study approach to focus on the experiences of people with disabilities and their families in peripheral communities in Bahia, São Paulo, Minas Gerais and Rio de Janeiro, particularly emphasising the role of mothers and mothers' networks in disability activism. Brazil serves as a compelling location for a study of intersecting systems of oppression owing to its unique history defined by the transatlantic slave trade. As demonstrated by the case of Zika, these systems continue to shape today's socioeconomic inequality along lines of race, gender and disability, which I will expand on in Chapter Three.

Research questions

The gaps outlined above led to the generation of the following research questions, which are underpinned by a Critical Disability Studies framework:

Main research question:

How do the experiences and actions of mothers of children with disabilities in peripheral communities in Brazil challenge dominant understandings of disability activism?

Research sub-questions:

1. How are the experiences of mothers of children with disabilities shaped by information and service provision in peripheral areas?
2. How do mothers' individual and collective actions resist failures of the state to adequately provide care and support for children with disabilities and their families in peripheral areas?

While answering these questions, the research also pursued the following objectives:

1. To design a participatory research project committed to social justice using research methodologies that help address the gap between parents and disability activists. This is achieved by engaging both groups and including mothers of children with disabilities who also have disabilities themselves; disability activists; mother-leaders of mothers' networks, and other relevant civil society organisations who represent members of peripheral communities.
2. To ensure that the project satisfies the non-academic aims of the project partners, including data collection with the purpose of advocacy towards ensuring the rights and dignity of children with disabilities and their families in peripheral communities.
3. To ensure that participants and project partners benefit from their participation in the project, via financial or in-kind remuneration, connection with other activist networks, access to information, services and support, and opportunities to engage in different projects and advocacy.

Key theoretical frameworks

This thesis is grounded in a Critical Disability Studies (CDS) framework, which challenges traditional, individualised, and identity-based understandings of disability by reframing it as a product of intersecting social, political, and environmental forces. The underpinning theoretical work is Kafer's (2013) political/relational model of disability, which positions disability not solely as a medical or individual issue, but as something shaped by relationships, power structures, and broader systems of oppression. This model provides a foundation for understanding how the lived experiences of mothers of children with disabilities in Brazil are not simply responses to individual impairment, but are influenced by their socio-political environments. By adopting an intersectional feminist lens within CDS, this thesis aims to address a gap in disability activism literature, where parental perspectives, particularly those of mothers outside mainstream organising structures, have often been overlooked. This framework also informs the study's participatory methodology, centring on mothers' perspectives, including those of mothers with disabilities from peripheral communities, in the analysis.

To explore the experiences and actions of these mothers, the thesis draws on Dokumaci's (2019) concept of microactivist affordances, which highlights how individuals create access and navigate within contexts of constraint. Microactivist affordances is extended through the development of the concept of *shrunken affordances*, a term I use to describe the limitations imposed by the intersecting oppressions of race, class, gender, social class and geographic marginalisation in peripheral areas and the possibilities arising from these

limitations. Combining this with Puar's (2017) theory of debility and Nixon's (2011) notion of slow violence, the study conceptualises how environmental and institutional neglect can debilitate both children and their mothers. In analysing mothers' actions, the thesis expands on Dokumaci's later work on people as affordances (2020) to capture how mothers themselves build infrastructures of support via mothers' networks and perform acts that go beyond normative expectations of mothering. These actions are further theorised through the concept of (macro)activism - collective activism that emerges from microactivist networks and seeks broader systemic change. Together, these concepts offer a rich, intersectional lens for understanding disability, care, and activism of the periphery.

Contributions of the thesis

The theoretical contributions of this thesis lie in its novel application of disability theories to studying experiences and actions of carers that enhance Critical Disability Studies by offering new insights into parent activism and providing a deeper theoretical understanding of how disability is experienced and alternative methods of resistance. This thesis also generates more data on parent experience and action in a non-Western context that takes an intersectional and post-structural approach. This contributes to filling the gaps in this area as identified in the literature review, laid out in Chapter One. The methods and theoretical underpinning of the project that commits it to a participatory approach with real-world applicability also generated data used by project partners in ongoing national and international advocacy to advance policy debates relating to disability, race and care. Specifically, project partners were able to draw on data generated by this research in public consultations about the proposed National Care Policy and in both formal and informal international advocacy using the UN human rights mechanisms. These practical applications will be elaborated in the methodology, Chapter Four and the conclusion, Chapter Eight.

Researcher positionality

This thesis forms part of my broader, ongoing work at the intersection of research and advocacy, rooted in partnerships with those with lived experience and shaped by my own. Growing up in a multiracial family with disabled members and assuming care responsibilities from a young age, exposed me, albeit not always firsthand, to the realities of ableism, racism and sexism entangled with unpaid care, bureaucratic struggles, and the systemic barriers disabled people and their families face. However, as I reflect further in Chapter Four, my positionality and privilege also have implications for shifting power imbalances whilst doing research in a global south setting, in a community that is not my own. Whilst I attempt to resolve these issues in multiple and ongoing ways, I do not claim to be able to

fully resolve them. Although it was not an initial aim, this research has deepened my understanding of my own family's experiences and how they intersect with broader structures of power and oppression, including gender, disability, race, and social class, both in the UK and globally.

Professionally, my background as a human rights practitioner and researcher, particularly in collaboration with minority and Indigenous disability activists, has significantly informed this thesis. Working at an international human rights organisation during my PhD shaped the content and direction of this research, allowing me to link it to practical advocacy and connect project partners with global human rights platforms. While Disability Studies, especially through my time at the Centre for Disability Studies at the University of Leeds, has profoundly influenced my academic learning, the most impactful education on disability and intersectional oppression has come from my lived experience and professional relationships. These experiences have driven me to critically reflect on whose voices are centred in academic and activist spaces, and who remains marginalised or erased.

Being a non-native Portuguese speaker brought both challenges and benefits to the research process. Learning Brazilian Portuguese was time-consuming, particularly due to the disruptions caused by the COVID-19 pandemic, but previous experience conducting research in another language helped me navigate the process. I mitigated language limitations by collaborating closely with project partners and native speakers, validating data through recorded interviews and conversation circles, and involving native speakers in transcription and translation. At the same time, conducting research in Portuguese expanded the literature base to include both English and Portuguese sources, enabled direct collaboration with non-English-speaking project partners, and allowed me to engage with participants without interpreters, avoiding the limitations this brings whilst fostering direct connection. Although not being a native speaker inevitably posed some limitations, it also helped flatten power dynamics by exposing my linguistic vulnerability, creating shared moments of humour, and demonstrating commitment to the research and the community.

Language

Translating concepts between English and Portuguese

Whilst I primarily conducted the fieldwork in Brazilian Portuguese, along with all other co-produced outputs from the project, the thesis is written in English in line with the regulations for the PhD programme. Where appropriate and relevant, Portuguese terms are presented with the English translation in square brackets, or vice versa. Translations and definitions of key terminology, such as 'mothers of children with disabilities', 'periphery', and 'people with disabilities', were addressed with the project partners during the research

project. Regular discussions about terminology and language occurred between the project team throughout the research and will be discussed further below. This input was invaluable, especially as a non-Brazilian researcher and a non-native speaker, to ensure I used the most appropriate, respectful and political language to describe the key findings.

Disability

Disability and impairment terminology is highly debated and continually evolving, with many terms historically used in derogatory ways that reinforced harmful stereotypes. Activists have pushed for change, advocating for language that is self-chosen by people with disabilities, reclaiming words like "crip," (Clark & Marsh, 2002) while rejecting others, such as "differently abled," which many consider patronising (Brown, 2013). The language used to describe disability reflects the political and social context, with discussions around "disability-first" versus "people-first" language being prominent. Some Western activists prefer terms like "disabled people" (Barnes & Mercer, 2003) while others support "people with disabilities," as seen in the international standard set by the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2019).

In Brazil, disability terminology has also shifted over time. Terms like "pessoas com deficiência" have been embraced by disability rights activists, while older labels, such as "portadora de deficiência" (carrier of disability), have been rejected (Sassaki, 2003). Despite this, some outdated terms such as ‘pessoas deficientes’ (deficient people), ‘pessoas excepcionais’ (exceptional people), ‘pessoas especiais’ (special people) and ‘pessoas com necessidades especiais’ (people with special needs) persist in everyday use, particularly among professionals and parents, rather than people with disabilities themselves.

For this thesis, I have chosen to use the term ‘people with disabilities’, which more closely represents the language of the project partners, participants and disability activists involved in the research. In respect to disability studies scholars and activists who prefer the English term ‘disabled people’, I will use this term when citing scholars who prefer this language or when talking about disability within a Western context. By doing so, I hope to reflect on my commitment to respecting the language choices of different communities and individuals.

Race/colour/ethnicity

Brazil takes a self-identification approach to define race in terms of skin colour, as either black [PT: *preto*], brown [PT: *pardo*], indigenous [PT: *indígena*] or yellow [PT: *amarelo*], which is broadly equated to East Asian ethnicity. The Black movement in Brazil, including the leading project partner, Vidas Negras com Deficiência Importam (VNDI) [EN: Black Lives with Disabilities Matter], currently use the term ‘negro’ to refer to the black and brown Afro

descendent population. The term ‘negro’, which had been used pejoratively, was reclaimed by the Black community to give space for the work of Black authors that challenge negative stereotypes, such as through the work of Conceição Evaristo. In respect of this, I use the equivalent in the English language, which is the capitalised ‘Black’, also used by the Black communities in the United States.

The Periphery

Related to language on self-identification, a key concept developed throughout the thesis is ‘the periphery’ [*PT: periferia*], which, I propose, contextualises intersectionality in the Brazilian context. Through the development of the research focus, the project partners were keen that the research should focus on ‘mothers from the periphery’. Whilst this was never rigidly defined, the project team loosely defined it through multiple conversations throughout the research process. The key defining characteristics that helped in the identification of participants and research sites included mothers from poorer socioeconomic backgrounds who were more likely to self-identify as Black or brown, more likely to be single, living in a peripheral area with poorer access to services and more likely to rely on public services than being able to pay for access to private services such as private health insurance.

Whilst I was discussing with project partners the correct terminology to describe the geographic dimensions of such experiences, several terms were suggested, based on local preferences that differ across the country, including *favela* [EN: slum] and *comunidade* [EN: community]. Since these terms have sometimes been used in derogatory ways, despite being reclaimed by some communities, we decided that the term ‘periphery’ was the most appropriate and widely understood.

Using the periphery as a social marker indicates a political identity shared amongst some of the research participants and by the partners. Whilst ‘the periphery’ is not a standard identity marker like race, class and gender recognised by institutions, the periphery, or *peripheries*, as Pedreira et al., (2018) use to stress the plurality and collective nature of this identity, is often used as a social marker by those living in or working in peripheral areas. The periphery, therefore, indicates a shared, yet plural experience not sufficiently captured by or synonymous to other social markers or identities. Director of the leading project partner, VNDI, Luciana Viegas, summarised as follows [emphasis her own]:

> ‘*Because it's not* just *about race, it's* also *about race… for example, a white person who lives in the periphery doesn't have access, because those who live in the periphery are mostly Black. We were placed there, but those who are there because of class issues, who don't have money, also have the same type of lack of access that a Black person has.’*

As suggested above, being from the periphery adds another layer of precarity to everyday life, yet it is also claimed as a collective political identity, which 'is one of the ways to create confluence that proposes a different dynamic in decision-making spaces and replaces the planned absence of the State' (Pedreira et al. p.30).

As will be further developed in the empirical chapters, I drew on an understanding of the periphery as a dual concept, both as a site of precarity and violence created by the state and absence of state provision and as a site of resistance through knowledge production and collective development of creative alternative solutions. I draw attention here to the manifesto created out of the first meeting of the International Network of the Peripheries, which states that peripheries are also characterised through,

> *'the presence of participatory collective models, movement and social organisations fighting for their rights and broadening the range of demands and actions towards improved democratisation of the city'* (Instituto Maria e João Aleixo, 2017, p. 5).

This duality was an essential objective of the research; not only did we want to know what the families' experiences looked like, we also wanted to know what they did to respond to their circumstances, individually, but also through social organising.

Structure of the thesis

The thesis begins with a literature review in **Chapter One**, on how parent experiences and disability have been framed in the existing literature. This chapter explores hegemonic, individual and charity framings of disability, the concept of familism in application to assumptions and policies on care and support, social, biopsychosocial and human rights framings and post-structural framings. This chapter explores models of disability through the development of the discipline of Disability studies, disability activism as framed within social movement literature and the challenges of understanding and conceptualising disability activism. The chapter examines how parent experiences have been framed through disability activism. It outlines the key gaps in the existing literature, including the biases of the literature in terms of Western conceptual framing, geographic location, lack of attention to gender, race, social class and other intersectional factors, limitations of the current conceptual frameworks and a depoliticised approach to studying parent experiences and activism.

Chapter Two reiterates the key gaps identified in the previous chapters and introduces a conceptual framework designed to address them. The presented framework draws on the work of Black feminist and Critical Disability Studies scholars to recognise that existing

Western frameworks for understanding disability are insufficient in explaining how disability activism emerges within racialised and marginalised communities (Schalk, 2022). It therefore applies a post-structural, political/relational model of disability. It combines Dokumaci's theories of microactivist affordances (2019) and people as affordances (2020) with an intersectional framework to include concepts of debility (Puar, 2017; Williamson et al., 2023) and slow violence (Nixon, 2011), which offers a novel way of analysing the experiences and actions of mothers of children with disabilities in peripheral contexts. Here, I also use and develop the concept of the periphery as a context of *shrunken affordances*, which expands on Dokumaci's (2019) notion of shrinking affordances. The Brazilian concept of the periphery helps to provide a contextual understanding of intersectionality and is developed in Chapter Five.

Chapter Three provides an overview of the historical and contemporary context of disability and activism in Brazil. It begins by examining the legacies of colonisation and slavery, highlighting their impact on motherhood and disability, and the creation of the country's peripheral communities. The chapter then follows the evolution of disability movements from the late 19th century, through the period of the Brazilian Republic, and explores early disability activism through democratic and health reforms. It further presents the democratisation process at the end of the 20th Century and the growth of disability activism in 21st-century Brazil, noting the challenges posed by the Zika and COVID-19 health emergencies. The second part of the chapter focuses on persisting inequalities in modern-day Brazil, with a focus on key issues including modern slavery, environmental racism, health inequity and issues of limited social protection, including disability welfare benefits and social assistance services, for children with disabilities and their families. This is contextualised against the current policy framework and ongoing issues of institutionalisation linked to poor social protection and care policies.

Chapter Four presents the methodology to answer the research questions, starting with a review of emancipatory and participatory research. The participatory disability research design approach with civil society partners is presented by discussing its different dimensions: positionality, power, complicity and reciprocity. This chapter describes the data collection methods, including workshops, visual creative methods, conversation circles, and interviews. It also outlines the participatory approach to abductive thematic analysis employed in the project to analyse the wide range of data collected. Lastly, a participatory evaluation of the methods is presented, addressing limitations of the study design and examining ethical considerations, such as vulnerability, sensitive topics, and workshop design.

Chapter Five is the first of three empirical chapters. It presents the main themes relating to the lived experiences of mothers of children with disabilities across the research sites. Themes include the medicalisation of disability and its implications, particularly in

overlooking the human aspects of care and a lack of information that meets the emotional and practical needs of parents during the post-diagnosis stage. The chapter also presents an overview of the issues in accessing state support within peripheral areas, including the lack of provision, dependency on the *Sistema Único de Saúde (SUS)* [EN: The Unified Health System], denial of social assistance and the resulting precarity. It also includes a reflection about the benefits of access to private healthcare plans, despite the issues in coordination between the private and public health sectors. The chapter summarises the context of what I term *shrunken affordances* within the peripheries, introduced in Chapter Two. The findings show that shrunken affordances severely limit the options available to families in accessing support and services in this environment, with serious consequences in terms of heightened precarity.

In Chapter Six, I apply Dokumaci's (2019) concepts of *microactivist affordances* and *people as affordances* (2020) to analyse mothers' individual and family-level actions to resist and how this is formed from a context of shrunken affordances. This framework reveals how actions that are often depoliticised as just another part of the care role employ strategies of world-(re)imagining, self-education, and fighting the system to construct new and habitable 'disability worlds' for their children (Dokumaci, 2019). However, I also discuss the possibility that mothers' microactivism can also be seen to adhere to neoliberal pressures to normalise their children through scientific and medical intervention (Frederick, 2017).

In the last and final empirical chapter, **Chapter Seven**, I look at mothers' microactivist networks and how they provide vital social support as part of infrastructures of care. Furthermore, I explore the different functions and objectives of these networks, including how they facilitate both mothers' microactivism at the individual level, via providing informational, emotional and instrumental support and (macro)activism at the structural level via ad-hoc campaigns and systemic civic engagement with policy and decision makers.

In the final chapter, **Chapter Eight**, I draw together the arguments developed throughout the thesis to answer the research questions. This chapter outlines the key contributions and limitations of the thesis, theoretically, empirically and methodologically, as well as contributions of the research for advocacy. It finally provides some suggestions for future research directions based on the findings and limitations.

Chapter 1: Mothers and Disability Activism

1.1 Introduction

This chapter offers an overview of the current state of the literature to reveal to what extent parent experiences and actions have been framed as disability activism. I begin the argument here to understand to what extent the existing literature can and does answer the main research question set out in the previous chapter: how do the experiences and actions of mothers of children with disabilities in peripheral communities in Brazil challenge dominant understandings of disability activism? Defining disability activism is primarily influenced by current understandings of what both 'disability' and 'activism' are and do. To understand disability activism, it is vital to start with a sense of how conceptualisations of disability have evolved and been influenced and what their implications have been for people with disabilities and their families.

I begin here by looking at framings of disability and parent experiences and actions within the literature to provide an overview of the main theoretical approaches to disability before looking at how this is applied to disability activism in the following section. As described in the introductory chapter, I use 'experiences and actions' rather than activism to widen the terms of inclusion and better interrogate how far mothers' actions and experiences are conceptualised as activism. I do this purposefully in recognition that these actions and experiences are often depoliticised or overlooked through some framings.

The chapter commences with an overview of the main framings of disability within the academic literature and how far these have addressed the parent experience. I start by looking at parents more broadly, since some literature does not differentiate between mothers and fathers. Secondly, I discuss the framing of disability activism, considering how far the dominant frameworks used to explain activism are applicable. Following this, I present an overview of the contested space of parents and disability activism, focusing on mothers, laying out the key debates and issues. Finally, I present the literature gaps to explain how mothers' experiences and actions in peripheral contexts are part of disability activism. In Chapter Three, I will describe how some concepts and frameworks in the literature discussed in this chapter play out in the Brazilian context.

1.2. Framing disability and connecting familism

In this subsection, I loosely group the framings of disability and parent experiences into three parts. The first brings together what I consider to be the hegemonic framings of disability, covering medical, individual, and charity models, grouped in recognition of their overlap. I label them as hegemonic because they are widely understood to be the most prevalent and often default understandings of disability across many societies and cultures, albeit taking different forms. Mike Oliver (1990) reminds us that we should not overly focus on models at the risk that debates over terminology will distract from the core issues of disability, which are rooted in oppression, discrimination, inequality, and poverty. However,

it is these hegemonic framings I am to present that are mainly rejected by disability activists as contributing to and reinforcing the oppression of people with disabilities.

An additional section on *Familism* is also highlighted in this subsection, as I argue that this approach to disability and parent experience is most closely connected to hegemonic framings. It is relevant for the context of the study, as it is concerned with the interconnected nature of experiences of children with disabilities, and mothers who are held responsible for their care under familist policies that play out at the intersection of multiple oppressions. Secondly, social, biopsychosocial and human rights models are presented together, in recognition that these framings also overlap and have been largely promoted by mainstream disability rights movements worldwide, in dialogue with an academic theoretical development in Disability Studies.

The final grouping is post-structural and new materialist framings, which includes approaches to framing disability through the field of Critical Disability Studies, influenced by other fields of study and social justice including feminism, Critical Race Theory, decolonial and postcolonial theory and Queer theory. These final framings are to be drawn on for the theoretical framework of this study, as will be more fully outlined in the following chapter.

1.2.1. Hegemonic, medical, individual and charity framings

Conceptualisations of disability are closely tied to cultural, historic, political and religious readings of bodies, humanity and illness, and, as such, have varied across location and time. Such conceptualisations have been reflected in the way that different cultures and societies have treated people with disabilities throughout history, ranging from reverence to rejection, and continue to exert influence on current understandings of disability (Munyi, 2012). Whilst Disability Studies scholars often shy away from focusing on family members through fear of further marginalising the experiences and voices of people with disabilities themselves, I argue that it is possible to avoid this, but also essential to study both how and why they intersect. I aim to present a brief overview of some of the dominant framings of disability throughout history as presented in the literature, whilst reflecting on the implications for people with disabilities and their families.

In many cultures, conceptualisations of disability have stemmed from belief systems that link illness and impairment to various spiritual explanations. Recent work suggests that not all spiritual or traditional belief system explanations of disability have or previously had negative connotations. For example, studies which explore how African and Indigenous cultural conceptions of social interconnectedness and humanity, or *Ubuntu,* suggest that people with disabilities are viewed differently and perhaps more positively than in an individualised, Western view, which prioritises independence (Mji, Gcaza, Swartz, MacLachlan, & Hutton, 2011; Owusu-Ansah & Mji, 2013; Stienstra, Baikie, & Manning, 2018). There is also evidence that the importation of Western beliefs, religion and approaches to disability during colonisation changed how disability came to be viewed around the world. For example, Brégain (2016) notes that in Algeria, ideas imported from France disrupted traditional approaches to blindness in North African Islam, in which blind people were often seen as closer to Allah and, as such, could assume high social positions. I

highlight here the relevance of considering how conceptualisations of disability have been influenced through processes of colonisation, especially in postcolonial contexts such as Brazil, which I will further explore in Chapter Three.

Negative conceptualisations of disability, whether existing or more recent, remain present across cultures and belief systems. Examples include disability as suffering and sin in Christianity and Buddhism (Schumm & Stoltzfus, 2007), animism in Ayurvedic humoral theory which sees disability and illness as linked to evil spirits and elements making up the body (Bamber, 1987), karma, demerit and the incomplete body in Buddhism (Burnard, Naiyapatana, & Lloyd, 2006; Naemiratch & Manderson, 2009a) and witchcraft in indigenous African beliefs that sees disability as a curse (Ndlovu, 2016), amongst others. These ideas have influenced and continue to influence society's understandings of disability, often contributing to pitying stereotypes and stigma attached to having an impairment. I draw attention here to how such negative connotations have first and foremost led to detrimental impacts for individuals with disabilities but also have had negative implications for the wider family.

In many cultures, negative framings of disability can translate into stigma towards other family members and particularly mothers of children with disabilities, who can be blamed for disability characterised as misfortune in different ways. For example, in Thailand, having a child with a disability has been linked to bad karma and punishment for sin in a current or past life of the parent (Naemiratch & Manderson, 2009b). Mothers in South Africa can be blamed for children's disabilities, abandoned by fathers and face domestic violence as a result (DSD & UNICEF, 2012; Mbanjwa & Harvey, 2023; van der Mark, Conradie, Dedding, & Broerse, 2019). Disability has also been viewed as a curse or punishment of women linked to witchcraft in Zimbabwe (Rugoho, 2019). Similarly, the concept of 'refrigerator' mothers, whose cold, aloof demeanour caused their children's Autism, was well documented in Europe and North America during the 1950s and 1960s (Burch & Rembis, 2014; Douglas, 2014; Langan, 2011). I argue that this concept has helped to reinforce the notion that disability is an individual or family matter, especially where the cause is attributed to women. 'Dealing with' disability, including providing care, is thus seen as a responsibility of the person or women family members, reinforced by gendered stereotypes related to care.

Related to cultural understandings of disability as individual or familial, most of the dominant disability discourse in the 20th Century can be explained by the medical model of disability. The medical model is linked to the individual model, which sees disability as a problem of the body owing to limitations or losses in physical or psychological functioning (Oliver, 1990). This conceptualisation sees disability as illness or disorder and therefore an individual medical matter, whereby a person needs to be fixed or cured to align as closely as possible with current conventional ideas of a 'normal' body and mind through medical or biomedical intervention.

The medicalisation of disability is linked with the modern view that medical professionals are experts and hence have had extreme control over the lives of people with disabilities. This control extends to 'where they should live, whether they should work or not, what kind of school they should go to, what kinds of benefits and services they should receive and in the case of unborn disabled children, whether they should live or not' (Oliver, 1990, p.4).

Through the medical model, deviation from the 'norm' is presented as a tragedy for the individual, who is simultaneously pitied and portrayed as a burden on society (Barnes & Mercer, 2003), or, I add here, their family. Furthermore, disability viewed through the medical model pays no attention to the role of society in disablement - to be further touched on in the later section on *Post-structural framings and critical disability studies (CDS),* and elaborated more fully in the following chapter, hence its individualisation and reinforcement of disability as an individual and, by implication, family matter, or a matter for medicine and public health.

The growing influence of biomedicine has impacted how disability has been medicalised, particularly during the post-war period when links developed between biological experimentation, places of healing and health regulatory institutions (Quirke & Gaudillière, 2008). Through emphasising the biological elements of disability, medicine and research are used to develop treatments and cures. According to Henri-Jaques Stiker's history of disability, as we have normalised health and the ideal body in the modern world through modern medicine and the ability to control our appearances, disability and difference have been pushed further to the margins of normality and acceptance (1999). Inevitably, biomedicine has become a prevailing frame in the burgeoning area of global health and is defined by Koplan et al. as 'a notion (the current state of global health), an objective (a world of healthy people, a condition of global health), or a mix of scholarship, research, and practice' (2009, p. 1993). The consequence is that the responsibility of the state to provide for its citizens with disabilities is reduced and instead placed with people with disabilities to become 'normal' through medical intervention. In the case of those who cannot achieve 'normalcy' and who continue to rely on care and support, there is more reliance on the charitable nature of their families and communities.

In the past, religious organisations and, more recently, philanthropic and charitable organisations, including those established by parents, have taken a charitable approach, often referred to explicitly within Disability Studies as the charity model. Arguments from disability rights activists in the latter part of the 20th Century posit that this framing promotes inequality between people with disabilities as beneficiaries and the benefactor and forces dependence instead of promoting rights (Drake, 1996; Lamichhane, 2015). The charity model is therefore based on the individual model, but with a more paternalistic view that people with disabilities, and family members by proxy, are victims of misfortune deserving of pity and help, allowing the benefactor to feel superiority in their enactment of religious or moral duty (Fleischer & Zames, 2011). Parents have often taken part in reinforcing such framings through establishing charitable organisations that take this stance and engage in activities that reinforce the charity model of disability. As criticism of these approaches has grown, the role of parents who claim to promote more progressive disability approaches is still questioned by disability activists and scholars, as will be explored in later sections.

Furthermore, the charity model has been used to expand on negative traditional or religious beliefs about disability. Chander (2014) writes about how in India, existing Hindu beliefs and ideas of karma that saw disability as the result of sin in past life, combined with charity model ideas imported by evangelical Christian missionaries in the colonial era. These combined to influence a charity model of disability that left most work on disability to

religiously guided charities, trusts and foundations (ibid). This framing conveniently relieves pressure on the state to provide for its citizens with disabilities by designating disability as a matter of religion, philanthropy or family. Care and support of people with disabilities is consequently framed as a charitable act, reinforced by a lack of policies that allow people with disabilities autonomy to make choices about their care. Framing disability in this way reinforces power imbalances between carer and cared for through notions of pity and moral superiority (McLaughlin, Goodley, Clavering, & Fisher, 2008). Significantly, the charity model reduces the humanity and therefore agency of people with disabilities, positioning them not as full citizens with rights but as passive receivers of benevolence at the mercy of those around them, most notably the family unit. In conclusion, hegemonic conceptualisations of disability that invoke individual, medical and charity framings are deeply implicated in the persistent marginalisation and exclusion of people with disabilities worldwide, as well as the oppression of women and girls responsibilised for necessary care and support.

1.2.2. Familism and care

The conception of care endorsed in this thesis is one that rejects traditional understandings of care. Traditional understandings of care tend to focus on physical activities and have been criticised for assuming one-directional care that divides the carer and the cared for as two parties in a care relationship (Morris, 2001) and reinforcing gendered care roles. Through the hegemonic framings of disability presented so far, beyond charitable and religious organisations, it is family members who are required to take on these traditional care and support roles for people with disabilities in the absence of support from the state. Gesser et al. (2022) suggest this to be framed as *familism*, which they define as a patriarchal capitalist welfare system where the family is primarily responsible for the well-being of its members. I consider this to overlap with the individual model of disability, whereby the individual, and by association, those around them, are responsible for disability. This framing contrasts with other philosophies, such as that championed by the Independent Living Movement, which prioritise self-determination, independence and inclusion in the community of people with disabilities (Hunt, 2019), responsibilising the state for the support necessary to achieve this. The implications of familism, therefore, are the reduced choices of both people relying on and providing unpaid care and support, namely, people with disabilities and women.

Influenced by gendered stereotypes, this places women and girls, including disproportionately those with disabilities themselves, in unpaid care roles, defined by UN Women as '*unpaid services provided by individuals within a household or community for the benefit of its members, including care of persons and domestic work*' (2022, p. 5). Whilst the extent to which gendered care varies between communities and is undoubtedly marked by socioeconomic class, race, disability and other social identity markers, international organisations estimate that 75% of unpaid care work is undertaken by women and girls worldwide (ILO, 2018; UN Women, 2022). As will be discussed later in the thesis, familism is relevant in the Brazilian context, where the situation of both people with disabilities and women caregivers is exacerbated by the absence of a comprehensive national care policy that would remunerate family carers who are unable to participate in the labour market owing to care responsibilities. This policy would promote the autonomy of people with

disabilities to choose and pay for their own care and provide adequate remuneration for those providing care work.

Lack of community-based support, caregiver support and access to services and systems are also linked to the institutionalisation of children with disabilities. We can see how this is indirectly related to familism, whereby families are expected to take on the responsibility of care and support of people with disabilities without adequate state services and support. For example, research indicates that stigma and medical model understandings of disability, coupled with poverty, a lack of social protection, community-based and caregiver support, are directly linked to institutionalisation of children with disabilities (UNICEF, 2024). Furthermore, the same report shows that institutionalisation of children with disabilities is more highly correlated with lower socioeconomic status and minority or migration status (ibid), illustrating the dimensions of intersectional discrimination in these trends.

Globally, it is estimated that up to 15% of people with disabilities live in institutions, where they are often isolated from their families and communities and denied economic, social and political participation (United Nations Department of Economic and Social Affairs, 2019). It is further estimated that children with disabilities make up one-third of children living in institutionalised settings worldwide and one quarter of all children living in institutions in Brazil (United Nations, 2019). We can therefore see this as a direct result of a lack of comprehensive policies that ensure the liberty of children with disabilities, which is exacerbated by dominant conceptualisations of disability through individual, medical and familist framings.

The literature on parent care experience can sometimes reinforce individualised and medical approaches to disability and familist framings of care. Mostly, this research does not define disability at all, or if it does, it is from a medical model approach that sees disability as a deficit. This body of research looks at the health impacts of caregiving, establishes the correlation between stress and depression and having primary caregiving responsibilities for children with disabilities (Gérain & Zech, 2019; Masefield et al., 2020; Vale, Alves, & Carvalho, 2020), the emotional impacts of dealing with a disability diagnosis (Bravo-Benítez, Pérez-Marfil, Román-Alegre, & Cruz-Quintana, 2019; Da Paz, Siegel, Coccia, & Epel, 2018) and the positive impacts of peer support on parents health and wellbeing (Bray, Carter, Sanders, Blake, & Keegan, 2017; Lancaster et al., 2023; Tomczyszyn, 2019). However, a medical model approach with inadequate analysis of social factors in the experiences of people with disabilities and caregivers can reinforce the assumption that higher rates of stress and anxiety are due to the presence of disability itself. Furthermore, this can position people with disabilities and caregivers as passive, as it reinforces the notion that disability is located in the body and that social intervention is therefore irrelevant. As such, whilst valuable in understanding some of the health impacts of caregiving, this research does little to challenge hegemonic stereotypes of disability and tells us little about the social dimensions of disability and care.

Feminist disability scholars who work on care critique the limitations of such conceptualisations. The critical understanding of care used within this thesis is influenced by these works, which have developed more expansive care concepts such as care-webs, informal community care, and kinship care related to disability justice (Piepzna-

Samarasinha, 2018), political-feminist ethics of care (Morris, 2001; Gesser et al., 2022), and access intimacy (Mingus, 2011), rooted in calls to redefine the essential characteristics of humanity to include dependency rather than focus solely on autonomy (Kittay, 1999). Furthermore, I reiterate that expanded understandings of care recognize that care can be reciprocal. In her analysis of care relationships, Erevelles uses Kittay and Ahmed's ideas of reciprocal care relationships as 'affective economy' (or emotional exchange between bodies) that 'enables a recognition of disabled subjects as social subjects located within reciprocal relationships that bind them to other bodies, and that, in turn, bind them to communities.' p.174. This feminist disability studies understanding of care interrogates the gendered economy of care and how care might be conceptualized beyond the traditional conceptualisations that reinforce familism. In the context of mothers raising children with disabilities in Brazil's peripheries, what other acts not traditionally defined as care, might be necessary to ensure their survival?

1.2.3. Social, biopsychosocial and human rights framings

The social model

The challenge of the hegemonic framings of disability so far presented occurred in the context of the post-war era and significant social and political change. The disability rights movement in the industrialised West accelerated at the same time as the emergence of other contemporary social movements which also challenged the status quo and led to a 'redefinition of disability by disabled people and their organisations' and development of the social model of disability (Barnes, 2003, pp. 2–3). Key contributions were made by Goodley et al. (2019), who refer to it as the foundational disability studies scholarship, in conjunction with the disability rights movement. Firstly, the distinction between impairment and disability made by the UK-based activist group the Union of the Physically Impaired Against Segregation (UPIAS, 1975) enabled analysis of disability as a social construct rather than a medical phenomenon through the social model of disability. Secondly, the crucial recognition of the oppression of people with disabilities as a group in both academic literature and by the disability rights movement (Thomas Shakespeare, 2010) and focus on the removal of barriers, instead of placing the onus on the impaired individual to 'adapt', reframed disability as a societal issue rather than an individual or family issue.

Furthermore, exploration in foundational disability studies interrogated the language we use to talk about people with disabilities, impairments and disability and uncovered how this creates stigma by reinforcing medicalised, paternalistic and negative stereotypes (Clark & Marsh, 2002; Linton, 1998). According to Barton, 'being disabled involves experiencing discrimination, vulnerability and abusive assaults upon your self-identity and esteem. Disability is thus a form of oppression which entails social restrictions' (1996, p. 8). This new period of scholarship was principally concerned with the experiences of people with disabilities themselves. As people whose experiences had long been marginalised and depoliticised through hegemonic framings of disability, establishing a political disability identity aligned with the recognition of group oppression through applying the social model was critical. As a result, the new discipline and related activism were less concerned with,

and even actively opposed to, platforming the experiences of family members, who were often viewed as perpetuating negative framings and leading activism for their own interests. However, McLaughlin et al (2008) recognise that family carers have therefore become a particularly neglected topic in disability studies, including the gendered economy of care that places women largely in positions of care for relatives with disabilities. Thus, whilst the sharp criticism of the hegemonic view of disability, including leadership of families, was indeed necessary, it resulted in a sidelining of key issues within activism and scholarship, as will be elaborated on in the following subsection.

The biopsychosocial model

Another model of disability that was influenced by the foundational disability studies scholars and activists, and rooted in the social model, is the biopsychosocial model. As noted, the influence of biomedicine and Global Health policy has played some part in ensuring that the medical model of disability has been hegemonic throughout modern societies. This hegemony prevails despite the efforts of disability rights movement and disability studies scholars to challenge this view through new framings. For example, the International Classification of Impairments, Disabilities and Handicaps (ICDH), published by the World Health Organisation in 1980 was severely criticised by disability rights activists for taking a medicalised approach to disability and therefore was subsequently revised and replaced by the International Classification of Functioning, Disability and Health (ICF) (Hogan, 2019). Both of these classification systems, promoted by the WHO and other international global health organisations, have significantly influenced how disability is understood globally.

Essentially a tool for identification of 'disability', the ICF proposed a new biopsychosocial model which was designed to be somewhere between the medical and social models and applied equally to those with and without impairments to measure health and functioning. The biopsychosocial model encapsulated in the ICF was celebrated by some disability rights activists for moving away from the medical model and promoting a human rights understanding of disability (Hurst, 2003). However, others criticised it for having its roots in the medical model and taking a categorical approach that makes classifying what counts as disability essentially a political and economic decision (Bickenbach, 2009) despite being presented as apolitical (Barnes, 2012). Ultimately, a biopsychosocial model is an improvement on hegemonic framings but still falls short in explaining experiences of people with disabilities and their families, as well as excluding many from the category altogether.

The human rights model

Despite the continued use of the biopsychosocial model, it was the social model of disability that came to foreground the CRPD (United Nations, 2006) and the human rights approach to disability. Whilst the social model provides a lens through which to analyse disability, the human rights model is an approach with more practical application, based on strategies rooted in international human rights law (Lord, Guernsey, Balfe, Karr, & Nancy, 2012). It places more emphasis on people with disabilities as rights-holders, aiming to achieve equal rights and inclusion for citizens with disabilities through law, regulation, and rights awareness raising (OHCHR, 2012). The human rights model has received less critique and

more praise from disability rights activists and scholars, likely because of the considerable input from disability activists in developing the CRPD. There seems to be particular support for a human rights model from activists and scholars in the Global South, owing partially to its ideological grounding in the social model and its tangible success in transforming how disability has been dealt with in national and international agendas.

The CRPD also takes families into consideration, noting in its preamble the role of the family in promoting the rights of people with disabilities. It considers their need for protection alongside that of their family member with disabilities, to adequate standards of living and assistance from the state (United Nations, 2006). In addition, the Convention outlines obligations of the state in Article 23 to 'provide early and comprehensive information, services and support to children with disabilities and their families' (United Nations, 2006). These elements of the Convention are relevant to the context of this study, since it recognises that to uphold the rights of children with disabilities, it is necessary to ensure support, protection and access to information and services for their families. However, I note here that in reality, despite the progress made by the CRPD in creating tangible change for people with disabilities worldwide through disability laws and policies, there is still a long way to go in extending this to progressive care policies that would protect the rights of those relying on and providing care.

A possible explanation for this lack of progress is that, despite the recognition of the protection of family members of people with disabilities, the Convention itself fails to explicitly recognise the reason for the need for such protections. It was not until 2018 that the CRPD committee recognised 'discrimination by association' (United Nations, 2018) – the experiences of discrimination of those connected to the person with disabilities.

Furthermore, it was not until 2022 that the committee gave explicit recognition of the indivisibility of rights of family members with and without disabilities. They made key points that linked adequate standard of living, social protection and the impacts of the gendered nature of caregiving, whilst considering the case of an Italian woman caring for her daughter and husband who both had disabilities (Torrijos et al., 2022). I argue that these delays, twelve and sixteen years respectively after the Convention came into force, are reflective of the wider reluctance of disability rights movements to engage in discussions, the contentious nature of these topics[2] and the limitations of the human rights framework as a one-size-fits-all approach. Indeed, some global south disability activists criticise the CRPD definition of disability for excluding some disability experiences and note the difficulties in transforming its discourse to a communitarian, local setting (Chataika, Sibanda, Mateta, & Sunar, 2019). It appears that the sidelining of these issues within Disability Studies, as noted earlier, has filtered into the Human Rights space and influenced which and indeed *whose,* issues are considered as within the scope of disability rights activism.

[2] The contentious nature of recognition of discrimination by association directed towards family members and the gendered nature of care was confirmed to me by a CRPD committee member who worked on the 2022 communication on the Italian carer's case. It is also reflected in the long period of time between the submission of the case in 2017 and the committee's decision over five years later.

1.2.4. Post-structural framings and critical disability studies (CDS)

Foundational disability studies established itself as a discipline and laid the groundwork for new ways of theorising disability that were closely tied to modern disability rights movements at the end of the 20th century and based on the social model of disability. However, while being dubbed as 'white disability studies', (Bell, 2006), the discipline has been heavily criticised for discounting the experiences of the majority of persons with disabilities, who are located in the global south and often in rural areas (Chaudhry, 2019) as well as minoritised and racialised people with disabilities in the global north. These criticisms, along with feminist critique over issues of representation and diversity of thought within the field, led to the more critical turn that has occurred through inclusion of interdisciplinary postcolonial, queer and feminist scholarship (Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019). Reflecting a connection with Critical Theory, this new field of disability studies has been termed Critical Disability Studies, or CDS.

Post-structural framings of disability, as captured in CDS, view disability as a social construct created by societal ideas of normality, power and language, in a move inspired by the works of Michel Foucault and Jacques Derrida. Although it still has roots in the social model, CDS scholarship offers new insights that break out of the confines of previous hegemonic visions based on global north, western, physically impaired, male, white, cisgender, majority and middle-class experiences of disability, as reflected in foundational disability studies.

Intersectionality

An important contribution of the feminist movement to Critical Disability Studies in addressing this hegemony has been the concept of intersectionality. This concept developed from Black feminist activism and scholarship, and is usually attributed to scholars such as Audre Lorde, bell hooks, and Kimberlé Crenshaw, who coined the term in 1989, along with other members of the Combahee River Collective in the US. Crenshaw (1989) originally used intersectionality to explain how the discriminatory employment experiences of Black women in the US were qualitatively different from those of Black men and white women because they were defined by both sexism and racism. However, it is pertinent to highlight that Afro-Brazilian feminists such as Lélia González and Beatrice Nascimento were also applying intersectional concepts in their speeches and writings around the same time, and even earlier, during the period of the military dictatorship in Brazil (Mara Da Silva & Mbandi, 2022). However, their contributions were largely overlooked by the Brazilian white feminist movement then and remain undervalued within scholarship, both within and outside of Brazil. I argue here that an intersectional framework is often misunderstood as a Global North concept, whereas in fact it was also developed within the Brazilian context, albeit not being named as such until 1989 by Crenshaw.

From the 1980s onwards, the feminist critique of Disability Studies and the application of an intersectional lens diversified the field away from being male dominated (Morris, 1991; 1992; Wendell, 1989; Meekosha & Shuttleworth, 2009) and Eurocentric (Grech, 2009, 2015; Meekosha, 2011). This critique brought by an intersectional lens is linked to the criticism of the social model, or its dominance within the field. For example, Dirth and Adams (2019)

point out that the social model's tendency to present disability as a homogenous social identity for the aim of political unity suppresses the experiences of those with other marginalised identities. Nontheless, the usefulness of intersectionality in Disability Studies has also been questioned vis-à-vis the practical application in the emancipation of people with disabilities. This is largely owing to the complexities of methodology and a tendency towards exclusion of disability in intersectional analyses (Conejo, 2013; Meekosha & Shuttleworth, 2009). I argue that whilst this observation is valid, it does not mean that intersectionality cannot be used critically to explore the multiple layers of identity that exclude certain groups from the disability rights movement and Disability Studies scholarship. In the context of this study, I defend an intersectional analysis as a critical tool for considering the complex context of people with disabilities and women carers in peripheral communities, whose marginalisation is not only linked to a disability identity.

Postcolonialism and critique of the social model

As with Black feminist scholarship's contributions on intersectionality, postcolonial and decolonial scholarship has contributed to a shift in Disability Studies by helping to loosen the rigid paradigm in which Disability Studies operates. This paradigm is seen as limiting the application of disability theory across cultures, as it attempts to 'problematically transport[s] theories and methodologies developed within the Western academy to other global locations, paying only nominal attention to local formations and understandings of disability' (Barker & Murray, 2010, p. 219). As an example of this rigidity located at the forefront of the movement and disability studies, the social model of disability has been widely criticised for dominating the disability rights discourse and reducing the complexities of society and culture by creating mutually exclusive binaries, e.g. social model vs. medical model; individual vs. society; impairment vs. disability; disabled people vs. non-disabled people (Corker, 1999; Tom Shakespeare, 2006), carer vs. cared for (Green, Darling, & Wilbers, 2013). The main criticism here is that binaries give way to oversimplification of what is a complex experience, an oversimplification with which many people with disabilities cannot identify. Experiences such as poverty, person-to-person relationships and rural environments impact worldviews, which are the foundations for conceptualisations of disability in different contexts. Chaudhry (2019) argues that most disability theory does not extend to the experiences of people with disabilities in the global South, most of whom live in a context where lack of infrastructure, poor services and poverty are intertwined and therefore where the Western, liberal binaries of 'medical' and 'social' are not applicable.

Building on post-structuralism's focus on power relations and knowledge creation, postcolonial scholarship has also contributed to the field of critical disability studies by interrogating dynamics within the field of disability studies from a crucial postcolonial standpoint. Helen Meekosha (2011, p. 668) notes the irony of the discipline of disability studies imposing a colonial normativity, i.e. that there is only one, Western understanding of disability, whilst questioning body-normativity, stating that 'contemporary disability studies constitutes a form of scholarly colonialism'. In contrast, disability studies scholars from formally colonised nation states such as Australia, Canada, and Mexico have produced a body of work that interrogates colonialism, postcolonialism and indigenous experiences of disability. This work rejects Western interpretations of disability based on individualism and more recognition of an indigenous worldview that is relational in concept, reflected in a

worldview that focuses on community, wholeness and interconnectedness (Owusu-Ansah & Mji, 2013; Stienstra et al., 2018).

These contributions have led to broader conceptualisations of disability that go beyond the confines of disability studies and mainstream disability rights activism based on what Watson and Shakespeare call a 'strong' social model (T. Shakespeare & Watson, 2001) that imposes sharp binaries. Examples of this include Black feminist work on Black disability politics and frameworks of disability in the US (Bailey & Mobley, 2019; Schalk, 2022), work on Chicana feminism, the body and illness (Bost, 2010), work on communities and reciprocal care (Erevelles, 2010; Piepzna-Samarasinha, 2018), and work on Aboriginal and Torres Strait Islander conceptualisations of disability (Avery, 2018; King, Brough, & Knox, 2014a), amongst others.

Decolonial thought has also contributed to exposing ideas of bodily normativity in relation to the coloniality of power. Whilst Latin American decolonial thought has been influential in thinking about the colonial ideology of normality, there has been limited development and systematisation of thought in relation to CDS (Revuelta & Hernández, 2024), and especially within the Brazil context. However, there is an emerging body of work on Latin American decolonial critical disability studies (Greiner, 2024; Ferrari, 2020; Morán; Tiseyra, 2019; Munévar; Fernández Moreno; Gómez Castro, 2020), albeit dominated by scholars from Spanish-speaking Latin America. For this reason, there is perhaps less engagement with decolonial thought within disability studies and movements in Brazil, and relatedly, within the conceptual framework to be presented in the following chapter.

In addition to postcolonial studies contributions that have questioned Western body-normativity, emerging CDS work also interrogates the creation of impairment linked to capitalist and racist projects. This view of impairment juxtaposes the framing of disability as an inevitable and natural part of the human condition that has dominated disability studies scholarship and activism. It attempts to move away from negative and pitiful stereotypes of disability. The social model of disability and disability studies in general have hence been criticised by critical disability scholars for ignoring or downplaying the creation of impairment in analysis of disability (Bailey & Mobley, 2019; Barker & Murray, 2010; Gabel & Peters, 2004; Sherry, 2016) including disablement of the body and the land via processes of colonisation such as land appropriation of indigenous people, forced displacement, genocide and cultural genocide, extractivism and slavery (King, Brough, & Knox, 2014b; Meekosha, 2011; Jaffee & John, 2018; Ineese-Nash, 2020).

Furthermore, Alison Kafer (2013) points out that understandings of disability based on the social model have excluded certain impairments and disability experiences. Those excluded are notably those that are more likely to impact ethnic minority and poor communities, linked to environmental issues such as pollution or socioeconomic matters including access to healthcare, conflict and violence, and experiences of cognitive disability, chronic illness and pain (Kafer, 2013). Yet the social model and human rights models seem to ignore or shy away from recognising impairment-creating events as an element of disability conceptualisation.

It is important to note that impairment-creating events are not confined to the past, and that impairment creation continues due to ongoing processes such as structural health inequalities, institutionalised violence such as police violence, environmental degradation, conflict or displacement, produced through unequal access to resources and power. CDS scholars and activists using post-structural and new materialist frameworks emphasise that the effects of disability are unevenly distributed across global north/south, colonial-settler/Indigenous, rural/urban, gender, class, and racial lines. Hollinsworth (2013) contends that persistent racism and colonisation have both disabled Indigenous peoples in Australia, with and without impairments, and generated impairment through health inequities.

Similarly, discussions about the medical aspects of disability apply to marginalised communities where, without the right access to healthcare or preventative care, nutrition or sanitation, the creation of impairments, diseases, and other health conditions becomes relevant to conceptualisations of disability and its study. Yet these discussions, and the communities to whom they are appropriate, continue to be sidelined in activism that tends to prioritise a positive disability identity pride approach, as will be explored in the following subsection.

Continued prevalence of the social model

Despite the criticisms of the social model, disability scholars continue to defend its relevance, including in application to the study of impairment creation. For example, Colin Barnes (2022) argues that the social model is still applicable as a means of looking more broadly at social barriers, including racism and health inequality in the creation of disability, perhaps through a social model of impairment. However, this remains something that is yet to be resolved in most social model scholarship and requires expansion to work out the tensions posed by the juxtaposition of differing perspectives of disability. Helen Meekosha summarises the tension that is posed by Western disability identity pride and the realities of disability creation in the global south:

> *'Maybe it is too confronting to deal with the continuing disabling of people in the global South because in trying to claim the positives of a disability identity, it becomes difficult to acknowledge the overwhelming suffering that results from colonisation, war, famine, and poverty.'* (2011, p. 677)

I highlight that this tension must be acknowledged and addressed to advance disability studies scholarship, expand our understanding of disability to include Global South experiences, and seek new ways of including the most marginalised in society, activism, and academia. I attempt to draw on this tension throughout my thesis in order to analyse how, within a global south setting where multiple systems of oppression operate, disablement operates in a different way than is identified within much of the global north-dominated disability studies.

Whilst post-structural framings of disability have broadened understandings of disability beyond the western, cis, white, male-dominated perspectives of foundational disability studies and activism since the turn of the millennium, there has been relatively little explicit application of these framings to the parent experience. The little that has been done

suggests that binary approaches are insufficient and post-structural framings might be more applicable. For example, Carey (2009) indicates that many parents in the US view disability as a relational experience that affects not only the individual but those with responsibilities for them, as such, challenging the disabled/non-disabled binary approach. Furthermore, Green et al. (2013) note that a social model analysis has been applied to a majority of the literature on parent experiences, despite these experiences questioning the medical/social binary through their problematising of concepts of normality (Fisher & Goodley, 2007). Therefore, thinking of disability and the family can help to promote thinking in disability studies around human interconnection and reconstruct the binary of disabled and non-disabled bodies (Goodley, 2007). These criticisms echo those outlined above, yet most of the literature on parent experiences has been done in global north contexts. Therefore, there has been little application of cultural understandings of disability and parent experiences that differ from those in Europe and the US, including documentation of related activism.

In summary, Critical Disability Studies (CDS) emerged in response to foundational disability studies' narrow, Western-centric focus, by incorporating intersectional, postcolonial, feminist, and queer perspectives to challenge dominant conceptual binaries and highlight the diverse, context-specific experiences of disability, particularly of racialised, minoritised, and Global South communities. While underpinned by the social model, CDS critiques its limitations, especially in addressing the creation of impairments through structural inequalities, and calls for more inclusive, relational, and culturally grounded understandings of disability that extend to family experiences and peripheral contexts. In the following section, I will explore the implications of this interpretation of CDS for framing disability activism.

1.3. Understanding disability activism

Following the discussion about disability studies and disability theory, we must discuss how we theorise disability activism concerning how disability is conceptualised. Prominent British disability studies scholar Mike Oliver (1997) argued that the disability rights movement is a New Social Movement, which, according to Barnartt and Scotch, has been modifying and extending the frame of civil rights to include people with disabilities (2001). New Social Movement theorists argue that, unlike classical Marxist movements, new movements are less politically aligned, rooted in the socio-cultural sphere, centered on collective identities (e.g., gender, sexuality), address diverse rights-based issues, and arise from informal networks and structures (Buechler, 1995; Johnston, Laraña & Gusfield, 1994). Other disability studies scholars have disagreed that the disability movement is a new social movement, arguing that it is preoccupied with financial and material resource allocation and, therefore, is more of a liberation movement (Tom Shakespeare, 1993).

Disability activism rooted in identity

According to Nelson Pichardo (1997), identity and culture are the only defining features that set new social movements apart from traditional social movements, with personal identity

dictating movement participation and movement tactics oscillating from informal, public awareness raising campaigns to formal political institutionalisation. Applying this theory to disability activism assumes that disability identity and culture are sufficiently unified to form a collective identity. However, as demonstrated already in this thesis, disability identity is complex, contested, and individual; therefore, how we define those with disabilities and who identify with 'the movement' is imprecise and fluctuating. For instance, the 'disability' label represents a huge diversity of impairments and experiences (Grech, 2016; Tom Shakespeare, 2013), and people can move in and out of the 'disabled' category throughout their lifetimes (S. Barnartt & Altman, 2013). Beckett (2006) notes that even in the UK, often considered the 'birthplace' of the modern disability movement and social model, there is uncertainty about a shared disability culture, as the positive identity promoted by dominant voices may not reflect all members' views. The issue of collective identity is therefore closely tied to the issue of defining 'the disability rights movement' as a singular, unified social movement and individuals' identification with the disability category and identity, however and by whomever that is defined.

Disability identity based on a social approach also emphasises shared experience and recognition of social oppression (Tom Shakespeare, 1996), and that the social model of disability has given political unity to the disability rights movement (Conejo, 2013), solidified by the CRPD and by efforts to implement it around the world. This may suggest that the social model has provided the shared identity required of a social movement. However, more recently, post-structuralist and feminist scholars have criticised the mainstream disability movement's preoccupation with the social model and its exclusion of certain people and experiences through impairment/disability and disabled/non-disabled binaries (Gabel & Peters, 2004). For example, the mainstream movements' reliance on the social model, rigid disability identities and the sharp distinction from a medical approach, as earlier discussed, excludes certain marginalised communities who are impacted by health disparities but may not self-identify as having a disability, as well as many people with invisible disabilities and chronic illness (Kafer, 2013). Does this mean activism for healthcare access or pain relief isn't considered disability activism, and that those outside mainstream disability organisations aren't engaging in it? I suggest that definitions of disability activism are inherently political, tied to dominant narratives and whose issues are recognised or ignored.

Disability activism as a unified social movement

This brings up further questions about identifying disability activism as something that happens within disability rights movements as social movements. Oliver asserts that organisations *of* people with disabilities are counted as part of the disability rights movement, whereas organisations *for* people with disabilities are not (1997). Again, over-reliance on the social model provokes a binary disabled/non-disabled approach that does not reflect the messy reality of disability identity. As Allison Kafer points out, much time, effort, and money have been put into working out who 'counts' as disabled, and these boundaries have been repeatedly redrawn by different organisations and for various political purposes (2013). My intention here is not to undermine the crucial role that organisations of people with disabilities play in leading disability activism. Rather, I aim to highlight that the simplistic binary approach to disability identity and activism often leads,

whether unintentionally or, particularly in the context of governments implementing austerity measures, deliberately, to the exclusion of some individuals while privileging others.

The issues of binary approaches also apply to those who do not identify as having a disability and asks whether, if one does not identify as such, one can engage in disability activism, or be part of a disability movement. For example, Sami Schalk (2022) notes that Black disability politics does not necessarily rely on disability identity because members of Black communities do not always claim this identity for various reasons, ranging from access to diagnostic services and healthcare services to fear of disability stigma risking further marginalisation. This is a pertinent point considering the context of this study, as the Black population are more likely to live in peripheral communities in Brazil, a fact that is tied to their historic and ongoing oppression within the country. I reiterate here that framings of disability directly impact the enactment of disability activism, denoting who is included or excluded, both from mainstream disability organising and from what is seen and represented as disability activism.

Disability justice approaches to activism

Following on from postcolonial and feminist critiques of disability studies and activism, as outlined thus far, a number of disability rights activists with intersecting identities developed the concept of 'disability justice.' Mia Mingus, one of the first disability activists to write about disability justice, explains it as follows:

> *'Building an understanding of disability that is more complex, whole and interconnected than what we have previously found. We are disabled people who are people of color; women, genderqueer and transgender; poor and working class; youth; immigrants; lesbian, gay, bisexual and queer; and more. We are pushing for an understanding of how ableism affects all of our movements for justice. We are drawing connections between ableism and other systems of oppression and violent institutions.'* (Mingus, 2010, p. n/a)

Rather than a theory of disability, disability justice is a framework for community organising that does not centre traditional methods of rights-claiming but relies on mutual support, understanding and care to enable access, space, participation and change. It has emerged out of the existing work of people with disabilities whose identities and experiences sit between movements and expanded on as a guiding framework for cross-movement organising via ten principles (Berne, Morales, & Langstaff, 2018). Essentially, disability justice is practical as well as theoretical, echoing the links between disability studies and activism already outlined. In their work, Leah Lakshmi Piepzna-Samarasinha (2018) has focused on the central role of care within disability justice, highlighting that mutual support and informal care are not only useful for survival but are forms of resistance to structures of oppression by providing community-based survival strategies that do not rely on state structures. Informal networks of care are therefore even more necessary for people who are excluded by state disability definitions and support, impacting especially Black, indigenous, and racialised communities. Thus, the application of an intersectional lens in advocacy aims to ensure that those caught at the intersection between race, class, gender, sexuality and

disability are represented in social movements and political spaces where they might otherwise be left out but also aims to re-frame what we count as activism and resistance.

My purpose is not to resolve the question of whether the disability movement is a new social movement or not, but rather to highlight that a new social movement or even more general social movement framing is insufficient to analyse disability activism in all its forms comprehensively. This is because many of these forms take place outside of the confines of what counts as disability movement organising, or what I term mainstream disability organising or the mainstream disability movement. I now turn to disability activism related to the parent experience, another form of activism that is contested as being part of the disability movement.

1.4. Parent experiences: adaptation, advocacy and activism

As described earlier, parent literature in the fields of medical sciences often takes a biomedical approach that fails to critically analyse disability and care from a social, cultural or political perspective, hence reinforcing a depoliticised approach to care and disability through medicalised and familist approaches (Da Paz, 2018; Bravo-Benitez, 2019; Vale et al, 2020). I acknowledge the usefulness of some of this research's insight into the parent experience, especially in relation to providing health, social asistance and education support services and establishing the negative impacts of familist care policies on parent carers, albeit without making these links explicit. Yet, since this work also generally fails to provide adequate policy analysis, it limits the usefulness of the observations that do not fully consider the social and policy context and risks medicalising social issues. Furthermore, in much of this work, there is a lack of consideration of parents' actions that go beyond the 'care role' – including actions such as chasing diagnoses, battling inaccessible systems, challenging ableist attitudes and other actions that form part of the daily lives of parents of children with disabilities and are relevant to the question of parent activism.

Another body of work that rejects this medical framing analyses parent experiences through taking a sociological perspective, foregrounding the actions and agency of parents. However, much falls short of framing the actions of parents as activism, or indeed disability activism, preferring instead to frame their actions through the lens of agency and adaptive preferences (van der Mark et al., 2019), coping (Bulhões, De Almeida, Reichert, De Abreu, & Dias, 2020; Correa, Bonilla, & Reyes-MacPherson, 2011; Marsh, Brown, & McCann, 2020), capacity (Armstrong, Birnie-Lefcovitch, & Ungar, 2005; Lancaster et al., 2024) or advocacy (Adams & Galvaan, 2010; Bertilsdotter Rosqvist, Brownlow, & O'dell, 2015; Groce, 1999; Mbanjwa & Harvey, 2023; Rossetti et al., 2021; Wright & Taylor, 2014). A smaller body of research also looks at parents' roles in health activism (Unnithan, Pachauli, Chattoo, & Atkin, 2023), although this is not always explicitly defined as disability activism.

Framing parent activism as a social movement

Some of the research looking at parent experience and action draws on the social movement literature, and I discuss here whether this framing is relevant to analyse mothers' actions in the Brazilian periphery. Following the literature that discusses disability activism as a social movement covered in the previous subsection, Ryan and Runswick-Cole utilise new social movement literature in their UK study of mothers of Autistic children engaged in advocacy and activism (2009). Drawing on the work of Searle-Chatterjee (1999), they note that members of new social movements are likely to be members of the middle classes, using their cultural capital and educational assets to build networks for mobilisation.

Comparable research in Brazil has focused on the activism of middle-class and most likely white parents (Block & Cavalcante, 2014; Brégain, 2013), and similarly notes that approaches to activism taken by these families draw on their social capital as members of privileged classes. Examples include using personal contacts with people of influence, engaging in formal structures of rights claiming and setting up private charities that serve their needs and their children's needs. Whilst this may apply to the case of mainstream middle-class white parents organising in Europe, the US and Brazil, this does not fit the mother-led organising profiles that form the basis for the case study in this thesis and, therefore, needs to be interrogated.

Activism vs advocacy

There is no clear definition of parent activism of children with disabilities. There have been attempts to define the concept, but it has come from studies focusing on the global north, and terminology differs between studies and contexts. In their study of mothers of Autistic children, Ryan and Runswick-Cole (2009) define the connection between advocacy and activism as a continuum and separate advocacy (individual and family-focused) and activism (collective and wider society-focused) as two ends of a continuum on which mothers move back and forth. Other scholars use similar ideas with different terminology; for example, 'advocacy' describes individual or personal actions, and 'macro-advocacy' describes wider societal and political actions (Wright & Taylor, 2014).

Similarly, Burke et al. (2024) draw distinctions between individual advocacy – advocating for one's own child, peer advocacy – advocating for children of friends, and systems-level advocacy – advocating for wider change. This is a valuable framework for connecting and analysing the relationship between individual actions and collective action within the context of the complex parent experience. Yet, I agree with Ryan and Runswick-Cole's observation (2009) that parent activism does not fit neatly into the existing social movement literature on disability activism, as will be explored below. As such, in this study, I chose to use the term 'activism' and work to question and redefine this through the theoretical framework outlined in the following chapter.

Parent/activist tensions

Although parent activism has been important, especially in the historic development of disability rights movements in the early-mid 20th century, limited attention has been paid to their role in current disability rights activism (A. C. Carey, Block, & Scotch, 2019). This lack of attention to parents' involvement might be partly explained by tensions between parent

advocates, who mainly advocate on behalf of their children, and adult self-advocates who front organisations of people with disabilities. There are two broad camps of those who have written about parent activism more recently. Some view the role of parents as necessary and important (see Langan, 2011; Orsini & Smith, 2010; Panitch, 2008; Walmsley, Tilley, Dumbleton, & Bardsley, 2017). However, others view parents' activist roles as contentious, noting tensions between parental and self-advocacy (Ben-Moshe & Magaña, 2014; Jingree & Finlay, 2012) and a tendency towards paternalistic or medical approaches to disability whilst experiencing conflict with their own self-interests and societal pressures (A. C. Carey et al., 2019). There seems to be little concordance in the literature and very little that explores or questions these tensions in greater detail. There is much less agreement on what disability activism is and who can legitimately make claims under the framing of disability activism. As a result, 'parental activism is one of the most fraught aspects of the disability-rights movement, and this is not a new phenomenon.' (Lewiecki-Wilson & Cellio, 2011, p. 179).

A contentious issue to disability activists and scholars is how parents frame disability in their activism. In the literature on parents, mothers are often portrayed as upholding medical framings, including interventions based on the medical-industrial complex (Blum, 2007; Douglas, 2016; Frederick, 2017) or supporting charity framings of disability, which disability activists widely agree to be harmful. For example, Carey et al. (2020) document how parents established organisations that engaged in telethons to fundraise to support children with physical disabilities in the US, posing this as an obstacle to disability-led organisations' social and human rights-framed objectives that focussed on policy change.

Disability studies scholars point out philosophical differences between parent advocates and self-advocates in their approaches to Autism, and whether it should be viewed as a condition to be 'cured', as viewed by some parent advocates, or as neurodiversity to be celebrated, as is the view of many Autistic self-advocates (Bertilsdotter Rosqvist et al., 2015; Orsini, 2009; Orsini & Smith, 2010; Morais Brilhante et al., 2021; Langan, 2011; Douglas, 2016). Anne McGuire (2016, p.67) points out that violence against Autistic people has become normalized through cultural understandings which frame Autism as a 'pathological threat to (normative, liberal versions of) individual life', which must be guarded against through parental (mainly mother) surveillance via an awareness-raising framework of 'red flags'.

Other scholars have pointed out that families tend to be over-protective of adults with intellectual disabilities and therefore make decisions for them instead of supporting them in decision-making (Curryer, Stancliffe, & Dew, 2015; Haigh et al., 2013; Jahoda & Markova, 2004; Tsibidaki & Tsamparli, 2009). In summary, most studies on parent experiences within disability studies, including the small body of work on parent activism, largely reject a biomedical model and therefore use the social model of disability as an analytic frame for the disability experience, including the actions and experiences of parents.

Carey, Block and Scotch (2020; 2019) attempt to codify various issues outlined in studies of parent and self-advocacy by identifying five frames used by parent disability organisations in the US. They do this regarding how far organisations reflect the medical and social models of disability, ranging from pure social model to medicalisation focused on cure and

prevention. This framework, expanded from previous work, is based on the ideas of Charlton (2000) and Longmore (2003), proposes that organisations whose objectives align with the disability rights movement, particularly in emphasizing the social model over the medical model, promoting inclusion, and advancing the empowerment of people with disabilities (A. C. Carey et al., 2019) are counted as part of the movement. They conclude that in the US, parent-led organisations were viewed as 'sometimes' allies to organisations of people with disabilities and the disability rights movement, with this alliance dependent on where they sat on the spectrum between social and medical model framing.

Whilst I think that Carey et al's framework (ibid) is helpful in understanding parent organisation approaches in a US context, I question further application of an analysis based on the strong social model of disability and its binary, individualistic and Western-centric approach of conceptualisations of disability in theory and activism. The social model's distinctions between disabled and non-disabled and preoccupation with a rigid disability identity focus necessarily on the experiences of the person with a disability. However, this framing also erases the experiences of those who fall outside rigid disability definitions (and therefore mainstream disability organising) and those connected to people with disabilities through responsibility for care or support or impacted by discrimination by association.

Beyond mainstream organising and activism

For example, work by Morrison et al. (2022) notes that parents' everyday acts of resistance in New Zealand amount to subtle forms of 'everyday activism' that are powerful in challenging structures of ableism in society. Nonetheless, these actions would not be considered mainstream organising, not least because they occur outside of an organisational structure. Likewise, rigid conceptualisations of disability activism and how it does and should take place (Berne, Morales, & Langstaff, 2018; Piepzna-Samarasinha, 2018) can lead to exclusion of many groups of people from mainstream disability organising, including Indigenous people, black and people of colour, LGBTQI+ people, mental health service users, drug users, people with intellectual disabilities, homeless people and others situated at the margins of society.

This critique of rigid identity definitions is echoed by other scholars who warn against interpreting parenting of children with disabilities in binary terms, because the parent experience is complex and therefore necessarily embodies both medical and social model approaches to disability and activism (Green et al., 2013; McLaughlin et al., 2008; Singh, 2016). Yet, beyond these studies, much of the parent activism literature relies on this binary whilst also continuing to frame parent activism through the social movement literature, without making much allowance for historical or cultural context.

The scholarly work of parents of children with disabilities who also identify as disabled themselves may provide further perspective here. Liz Crow and Wendy Merchant (2019) give insight into how as disabled activists and mothers of children with disabilities, there are tensions between these dual identities that compromise or contradict personal principles of disability activism to secure inclusion or wellbeing for their child. Building on the work of Ryan and Runswick-Cole (2009), they define their advocacy as 'the act of supporting our children by being alongside them and…'interceding on their behalf' as well as teaching self-

advocacy skills to their children, so that they can speak for themselves' (Crow & Merchant, 2009, p.159). Whilst they separate advocacy from activism, which they see as aiming towards structural and cultural change, they acknowledge the blurred boundaries between them and the links between personal trajectories of advocacy that leads to activism (ibid). Their work indicates that simplistic framings of the parent experience fail to capture the nuance of parental actions that may not always fit a clear social/medical or advocate/activist framing.

In addition, framing activism through a disability social movement lens leaves difficult questions about the role of parents in advocating on behalf of their children or in supporting their adult children to advocate for themselves. This is especially relevant to those who need significant support, and understanding how their interests are represented if family members are excluded entirely from disability activism spaces that are not inclusive of all needs. The disability rights movement has been criticised for being dominated by specific impairment groups that exclude people with intellectual disabilities and psychosocial disabilities in a 'hierarchy of impairments' (Deal, 2003), owing to stigma around mental health and lack of capacity (Charlton, 2000). Mainstream movements can and do exclude those who might rely on family members for support, and therefore, this criticism goes some way towards explaining the separation between parents movements and mainstream disability movements.

I note here that self-advocacy groups led by people with intellectual disabilities have contributed hugely to the advancement of the reframing of activism within disability activism spaces and contesting both their exclusion from mainstream organising and parent organising (Petri, 2018). However, most of these groups are located in the Global North, where (to a limited extent), social assistance policies allow paid personal assistants to replace unpaid family members, and access to quality inclusive education allows for the development of self-advocates autonomously, away from the controlling gaze of parents. Whilst there is evidence of burgeoning self-advocacy work (Ballard, 2024; Goldberg & Kleintjes, 2022), in many locations in the global south, and in marginalised communities within the global north, such supports are a luxury, and have contributed to the entrenched marginalisation of this population, and continued reliance on family members, including for advocacy.

Single-axis framing

I highlight here another clear gap within some of the parent activism and advocacy literature, which is the lack of attention to intersectionality, and particularly to gender. Traustadottir noted that early work on parent carers lacked a gender analysis and, therefore, ignored the role of mothers in the unpaid care of children with disabilities and how this extends into wider activism within the community (1991). The recognition that women, namely, mothers, do a majority of the parental activism as part of this care work has continued to be surprisingly absent from later literature, which applies a limited gender analysis and tends to use the umbrella term of 'parent activism' or 'family activism' without analysing exactly who is involved (Bertilsdotter Rosqvist et al., 2015; A. Carey et al., 2020; A. C. Carey et al., 2019; Leiter, 2004; Morrison et al., 2022; Orsini & Smith, 2010; Walmsley et al., 2017). Many of these studies are historical accounts of how parent movements

developed in the UK, the US and Canada from the 1940s, where gender disparity is evident in that parent organisations were mainly started by mothers, but in some contexts, leadership roles were disproportionately taken up by men.

Some exceptions take a feminist CDS analysis of mothers' activism, framing it as an essential part of the gendered care role (Douglas, Runswick-Cole, Ryan, & Fogg, 2021; Ryan & Runswick-Cole, 2009; Ryan & Runswick-Cole, 2008; van der Mark et al., 2019). Whilst the lack of gender focus of the literature might be a reflection of a more equal gender balance in some contexts – indeed, I recognise that many fathers are increasingly carers and advocate for their children with disabilities – the lack of gender analysis across a large section of the parent activism literature is evident and points to a gap in understanding of how parent activism is very closely linked to depoliticised gendered care roles.

Although more attention has been paid to the role of gender in care and parent activism in the last two decades of parent literature, other intersectional axes have not received such attention. A stark absence is a thorough analysis of race, ethnicity, religion, and culture within parent activism literature and the domination of global north-focused studies. Where an analysis of culture, race, religion or ethnicity is included or the primary focus, studies are more likely to focus on perceptions and general experiences of parents and less likely to analyse actions and agency of parents in navigating or challenging systems to create access for their children, be it at the individual or systems level. Where immigrant families have been included in larger parent studies in the UK, for example, there lacks a comprehensive analysis of how race, culture and language also interact with disability, care and activism experiences, which invisibilises these potential differences and places white, English and British as the norm (McLaughlin et al., 2008).

This absence occurs in the literature despite other research showing that ethnic minority families' experiences of intersecting identities can significantly mark disability experiences. For example, research in South Asian families in the UK shows that experiences and access to support are shaped by Islamophobia, migration history, language, cultural norms and religion (Heer, Rose, & Larkin, 2012; Rizvi, 2017). Furthermore, Ben-Moshe and Magaña point out that intersectional factors such as race, language, class and location impact specific communities in accessing health care and therefore accessing medical diagnosis that allow them to access disability services (2014). There is therefore a lack of nuanced research about how parents advocate for their children to resist not only disability discrimination but also discrimination on account of language, religion, immigration status and ethnicity and how these all intersect.

Adaption and agency

Where there is a focus on the actions of parents in informal contexts outside of mainstream organising in the parent literature, it is usually framed as 'adaptation', 'agency' or 'resistance' rather than 'advocacy' or 'activism' within a social movement framing. That said, the different framings do not mean that everyday actions at the individual level are not similar, as already suggested earlier in the blurring between advocate and activist roles (Crow & Merchant, 2019). For example, in their study of Black mothers of children with disabilities in urban settlements in South Africa, Van de Mark et al. choose to use the

concepts of Adaptive Preferences and agency from a feminist theoretical perspective to analyse the actions of mothers of children with disabilities in a South African urban settlement and how they navigate difficult contexts to reduce risk to their children (2019). Returning to the definitions presented at the beginning of the subsection, these actions are framed as advocacy or 'everyday activism' (Morrison et al., 2022) in other contexts and studies. However, the South African study also highlights the limits of political organising within spaces where there are multiple layers of oppression and limited access to structures of power (van der Mark et al., 2019). This may, therefore, account for the lack of application of a social movement framing, in contrast to studies of the global north, middle-class mainstream organising studies that are more likely to fit social movement definitions.

Finally, regarding methodology in research on parent experience and activism, there remains two notable gaps. Firstly, there is lack of studies that adopt a participatory approach involving parents directly in the research process. While there are some important exceptions (e.g., Adams & Galvaan, 2010; Araújo, 2011; Kuper et al., 2021), and a vital, though limited, body of work led by mothers of children with disabilities, particularly from disabled, neurodivergent, or 'mad motherhood' perspectives (Crow & Merchant, 2019; Douglas et al., 2021), the field holds significant potential for further participatory research. Such work could foster community empowerment, enhance research ownership, and support the development of community-led, sustainable solutions. The second gap, is the lack of children's voices, which would offer important insights into their own parents' activism, especially during the adolescent and adult stages. Whilst including children's voices in this research went beyond its scope, I suggest that this is an important and overlooked area of research that could expand perspectives and inform approaches to parent activism and research.

1.5. Chapter summary

In conclusion, this chapter highlights gaps and inconsistencies in the existing literature surrounding disability and parent experiences and the applicability of existing frameworks to the context of mothers of children with disabilities in peripheral Brazil. A critical reading of the literature reveals a domination of a depoliticised, single-axis - focussed only on one identity characteristic or system of oppression - and Western-centric approach to disability activism, which fails on two critical fronts. First, it overlooks the intersection between the oppression of people with disabilities and women, particularly within the context of familial care policies, thereby dually depoliticising the experiences of disability and the experiences of activism as part of the care role. Second, it fails to account for the experiences and actions of people with disabilities and their families in peripheral contexts, where multiple systems of oppression intersect and shape people's lives and therefore people may not have access to or trust in formal spaces, such as mainstream disability organising that is dominated by the social elite.

The gaps identified in the disability literature, including the over-reliance on a 'strong' social model (T. Shakespeare & Watson, 2001), which neglects individual and collective agency, and the failure to consider the intersection of disability with gender, race, and class, contribute to a narrow, reductionist understanding of disability that permeates disability

activism spaces. Similarly, parent literature often portrays parents, particularly mothers, as passive figures in medicalised frameworks, failing to recognise their activism or the structural issues affecting their experiences. Moreover, the predominance of research from the US and Europe invisibilises non-Western experiences and racial dynamics, excluding these perspectives from mainstream disability organising itself as well as theorising about disability activism.

The dominance of these framings and geographic foci is significant because they underscore the gap in theorising about disability outside of Western, hegemonic contexts, particularly in environments where disability is not the sole system of oppression that parents' activism must resist. Providing an intersectional and non-Western lens could therefore offer a broader perspective on disability, advancing the conceptualisations of disability beyond the limited frameworks presented earlier in this chapter and challenging the latter framings rooted in the social model. This gap is deeply connected to the tendency of mainstream disability activists and movements—often male, white or majority, cisgender-dominated, and focused on the western goal of independent living—to overlook or downplay critical issues such as gender, race, sexuality, and care.

Just as how disability is understood directly influences how disability activism is enacted, including which issues and groups are prioritised within disability rights agendas, contentious issues like those discussed here are often sidelined. This notion echoes Patty Douglas's argument, who suggests that "working the 'edges' between feminist and disability studies scholarship and activism on mothering, gender and care and their conflicting views opens a space of important questions about intertwining histories of oppression and struggle, as well as the possibility of releasing new, and potentially transformative stories" (Douglas, 2016, pp. 83–84). These critical issues should be placed at the centre of disability studies and activism. They should no longer remain on the margins, but instead, be the focal point for rethinking and reshaping both the theory and practice of disability activism. In the following chapter, I will present a conceptual framework that addresses the gaps outlined, taking a critical disability studies approach rooted in post-structural disability frameworks.

Chapter 2: Mothers as activists: a conceptual framework

2.1. Introduction

The previous chapter identified the key gaps and inconsistencies in the existing literature on disability and parent experiences, particularly in the context of mothers of children with disabilities in peripheral contexts. A critical review revealed a dominant, depoliticised, Western-centric approach to disability activism that fails to address the intersection of disability, race and gender, particularly in familial care policies. Furthermore, it highlighted how the approach neglects the experiences of families in peripheral contexts, where multiple systems of oppression intersect. It considered the over-reliance on the 'strong' social model and a failure to consider intersectionality contribute to a narrow understanding of disability. At the same time, parent literature often portrays mothers as passive figures within medicalised frameworks, overlooking their activism.

Additionally, the predominance of Western, white, cisgender-dominated perspectives in disability research and activism marginalises non-Western and racialised experiences. These gaps highlight a lack of understanding of disability beyond hegemonic frameworks and emphasise the need for a broader, more inclusive approach. By centring issues of gender, race, and care, this study challenges existing conceptualisations and advocates for a rethinking of disability activism, drawing on Patty Douglas's (2016) call for an inclusive space that acknowledges the intertwined histories of oppression and struggle.

This chapter aims to map out the conceptual framework employed in this study, including the underpinning theoretical approach based on a political/relational model of disability (Kafer, 2013; Schalk, 2022) and the conceptual framework, based on microactivst affordances (Dokumaci, 2019, 2020, 2023), complemented by the concepts of debility (Puar, 2017) and slow violence (Nixon, 2011). I briefly recap the critical disability studies approach that serves as the theoretical underpinning of the project, namely, the political/relational model of disability (Kafer, 2013), explaining its relevance to the project. Finally, I will introduce the key concepts, rooted in a critical disability studies approach, that will be drawn on in the analysis of the empirical data.

This conceptual discussion is divided into two subsections. The first focuses on how to conceptualise the experiences of mothers of children with disabilities in the periphery and elaborate on Dokumaci's theory of microactivist affordances (2019) and its linkages with concepts such as debility (Puar, 2017; Williamson, Engel, & Fietz, 2023) and slow violence (Nixon, 2011). I develop this through analysis of the Brazilian concept of the periphery, touched on in the introduction. The periphery lends itself to a contextual understanding of

intersectional discrimination and what I call *shrunken affordances*, based on Dokumaci's concept (2019). The second subsection presents the concepts to be used in analysing the individual and collective actions of mothers in relation to shrunken affordances. I develop Dokumaci's theories of microactivist performances (2019) and people as affordances (2020) by applying them to new subjects, contexts and actions: mothers of children with disabilities in the periphery engaged in individual and collective actions. I develop this by introducing the concept of (macro)activism facilitated by mothers' microactivist networks in the empirical chapters, Five, Six and Seven, to expand the theory of microactivist affordances in new ways.

2.2. A political/relational approach to parent activism

The conceptual framework for this project is situated within CDS and aims to address the gaps outlined in the parent disability activism literature, as outlined in the previous chapter. I recap, as follows: an empirically and theoretically Western-centric and single-axis approaches that ignore or downplay other forms of discrimination that intersect with disability, connected to a domination of the social model and binary definitions of disability that underpin its analysis. Considering the context of this study as peripheral areas in Brazil, where gendered care of children is a societal norm, and there are divisions along social class and race lines in access to fundamental rights to state services such as healthcare and education, there is a need for a conceptual framework that can consider this complexity. I, therefore, present in the following section a CDS approach that will underpin the theoretical and methodological approach to this study.

As outlined in the previous chapter, the shortfall in previous approaches of disability studies is evident in the existing parent activism literature that does not account for the experiences of mothers of children with disabilities who do not fit into middle-class, mainstream organising in a Western context. As outlined in the previous chapter, these criticisms, along with feminist critique over issues of representation and diversity of thought within the field, led to the more critical turn that has occurred since the turn of the century. This has expanded perspective through inclusion of interdisciplinary postcolonial, queer and feminist scholarship (Dan; Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019). Critical disability studies, as a theoretical framework and methodology, can help address the gaps outlined previously and will serve as the basis for this project's theoretical and methodological framework. Following this outline, I will explain how a political/relational model of disability addresses the failures of the approaches taken in the existing literature and how it will further help to address the gaps identified.

2.2.1. Applying a Critical Disability Studies (CDS) framework

This project will draw on four key principles of CDS as outlined by Meekosha and Shuttleworth: 1) a rejection of a 'facts-based' natural science or purely biological approach that reduces complex social and cultural interaction, and presents disability as depoliticised; 2) a linking of theory and practice, meaning producing research that reveals power dynamics and is applicable by the communities it is produced with and about; 3) a commitment to self-reflexivity in terms of recognising its historicity, and the limits of its applicability outside of time and place and; 4) dialogue with culture but especially non-Western cultures (2009). These four principles will be elaborated on in application to this study, as well as other disability frameworks that I will draw on.

Rejecting a natural science approach, as suggested in principle one, addresses the issue of disability and, I add here, gendered care work. I draw on the work of Gesser et al., as described in the previous chapter, who problematise a familist perspective, which works with ableism, depoliticising disability to be seen as an individual or family matter (2022). This depoliticisation contributes to a framing of people with disabilities as receivers of charity rather than rights holders, hence legitimising familist care policies which, owing to historical injustices within a Brazilian context, are more likely to responsibilise poor, racialised women and girls in peripheral areas for unpaid care (ibid). Linking theory and practice calls for careful consideration of a methodology that strives to resolve tensions present within the topic as far as it can. Additionally, it should involve those most impacted, in this case, people with disabilities and carers, in the direction and production of research that can demystify the social processes and power dynamics that they are subjected to. I argue here that what is required goes beyond feasibility within the confines of a PhD thesis alone and therefore requires ongoing work with communities that ensures that research can be used in ways that contribute to ‘the struggle for an autonomous and participatory society’ (Meekosha & Shuttleworth, 2009, p. 47). I further elaborate on my approach to resolving these tensions in the methodology chapter.

Relating to principles three and four, it is stressed that through a CDS lens, conceptualisations of disability cannot be separated from sociocultural, historic and political contexts (Hall, 2019). This points to the need in this study for locally situated empirical research that draws on a wide range of theoretical and empirical work, including that which adopts non-Western-centric concepts and theories. The contributions of CDS from global south standpoints have expanded the disability theory that critiques Western hegemony and calls for 'a critical disability studies that is open, situated around prioritising, engaging with and learning about the Global South in its full complexity’ (Grech, 2012, p.52). Meekosha elaborates, criticising a disability studies that contests body normativity but not the centrality of colonialism, in that 'disability in the global South is firmly linked to northern imperialism, centuries of colonisation and globalisation' (2011, p. 671). Taking this as a

starting point, we can therefore start to question the hegemonic concept of disability and its related binaries as presented in the majority of the parent activism literature.

In many contexts, notably in the global South, disability is experienced in context and cannot be separated from the wider marginalisation of their communities. In these contexts, where lack of infrastructure, poor services and poverty are intertwined, Western, liberal binaries of 'medical' and 'social' (Chaudhry, 2019), 'disability' and 'impairment' and 'disabled' and 'non-disabled' are limiting (Corker, 1999; Shakespeare, 2006). Instead of viewing disability as a static identity category, viewing it as an analytical category and studying the connections with other historically constructed social categories through intersectionality, we can move away from a binary approach towards a political/relational model. An empirical application to the context of mothers of children with disabilities in Brazil may provide better understandings and meanings of disability activism and contribute to theory development.

What is implicit in the CDS framework presented thus far is that capturing the complex social and cultural interactions that must be considered calls for applying an intersectional framework. Although Meekosha and Shuttleworth acknowledge that the application of intersectionality has allowed the study of disability to align itself with other emancipatory theoretical works, they also question its application because disability continues to be overlooked by many intersectionality scholars (2009). However, more recently, CDS scholars have used the concept of intersectionality to expand conceptualisations of disability that go beyond application in the disability studies field and make critical interdisciplinary contributions.

For example, Sami Schalk's application of CDS and intersectionality illustrates how historical insights are essential to understanding current cultural understandings of disability. Schalk uses the example of how the system of racial categorisation interacted with disability to impact Black bodies by reinforcing each other to justify slavery, violence and oppression in the pre-civil war United States. She emphasises how this historical understanding can help us understand the relations between race and disability today (2017). It is essential to consider Brazil's postcolonial history and legacy of slavery in shaping contemporary experiences and activism in the periphery. My intention with this thesis is to contribute to Critical Disability Studies scholarship by incorporating an intersectional and historical analysis of how disability is produced and understood culturally. The following chapter sets this foundation by outlining the study's historical and political context.

An intersectional framework further helps to highlight the interconnectedness of struggles within communities and move away from an individualistic and single-issue approach to studying oppression. For example, Indigenous disability scholars in Australia have used intersectionality to stress that CDS cannot ignore how colonialism contributes to the ongoing disablement of all indigenous peoples, not only those with disabilities

(Hollinsworth, 2013; Soldatic & Gilroy, 2018). Contributions from feminist and postcolonial scholarship can, therefore, help analyse community-based disability activism in a Brazilian context since the emergence of social movements in Brazil, which have roots in the colonial period and resistance to colonisation and slavery. Today, this manifests in the key role Black women play in community organising, which remains largely overlooked in social movement literature (Perry, 2016). The role of women in community organising for disability activism in non-Western contexts is equally overlooked. This project intends to contribute to theoretical work that will contribute to both areas. This leads us to the CDS-based political/relational model of disability that underpins the theoretical approach to the study.

2.2.2. A political/relational model of disability

The conceptual framework for this study will apply a political/relational model of disability to the case study in Brazil, based on the work of Alison Kafer (2013) and elaborated in Sami Schalk's concept of (dis)ability (2020). The model fits within the post-structural approach of other CDS work, viewing disability as a social construct created by societal ideas of normality, power and language. These concepts and the post-structural turn of CDS were particularly influenced by Foucault's work on biopower (Foucault, 1977) and bodies, normalisation and abnormality in the 1970s (Foucault, 2003; 1978) and Derrida's (1976; 1978) work critiquing Western reliance on binaries. However, the framework also brings in elements of new materialism, following an ontological turn towards to recentring the body and material realities and less on the role of language (Feely, 2016). This refocusing on the material body as well as the construction of language and power is an essential element of fully understanding experiences in the peripheries.

Like some other CDS work, the political/relational model of disability is heavily influenced by feminist theory and crip theory, which draws on queer theory to critique and draw parallels between compulsory ablebodiedness and compulsory heterosexuality (McRuer & Bérubé, 2006). The political/relational model therefore has its roots in poststructuralism – engaging significantly with theorists such as McRuer - but also moves beyond this to engage with new materialism and refocus on the materiality of impairment creation and disability experiences. The political element of the political/relational is first and foremost 'a direct refusal of the widespread depoliticisation of disability' (Kafer, 2013, p. 8), including within the parent literature as pointed out in the previous chapter. This supports Meekosha and Shuttleworth's (2009) key CDS principle of rejecting a natural facts-based or biomedical understanding of disability, as presented, and analysing disability within its historical and sociocultural and political context. This political/relational model makes visible the processes that shape the embodied disability experience, the processes that create body and mind impairments in the first place, and which communities are impacted. Kafer (2013) elaborates to explain how a politicisation of disability asks questions about how disability is

used politically as a category to control, surveil, segregate and oppress certain bodies and minds. By applying this to the question of experiences of mothers and children with disabilities in the peripheries, we can also ask questions of their role in the subjection to, upholding or resisting of this process.

The political/relational model aims to question the binaries present and critiqued in earlier models of disability and apply them to the parent and activist literature presented above. First, the political/relational model critiques the distinction between mind and body. Schalk and others use the term *bodyminds*, referring to the interconnectedness of mind and body. This term is part of a new materialist feminist disability studies framework, as proposed by Margaret Price (2015) and also draws attention to mental and cognitive disability, which are often overlooked or underrepresented within Disability Studies scholarship and disability activism.

Secondly, the political/relational model questions the medical/social binary and the rejection of medical approaches by the strong social model. Whilst Kafer (2013) rejects situating disability within a medical framework, she asserts that the political/relational model makes space for medical intervention. Additionally, she cautions that medical approaches should be politicised by asking about who gets healthcare access and how (ibid). As discussed earlier, the relevance of the medical aspects of disability applies to racialised and oppressed communities who, without the proper access to healthcare or preventative care, nutrition or sanitation, are subjected to the creation of impairments, diseases and other health conditions, something equally relevant to conceptualisations of disability and its study. Under this framing, can activism for healthcare access be considered as a form of disability activism?

Thirdly, the political/relational model questions the disabled/non-disabled binary and the fixed disability identity, instead proposing viewing disability as a broader category (Kafer 2013). Expanding on this, Schalk (2017) proposes the term (dis)ability to refer to a system of social norms categorising, ranking, and valuing bodyminds. She suggests that disability is a historically and culturally variable category within this larger system. Similarly to other post-structuralist disability scholars who use a backslash (/) to separate dis/ability and trouble the concept of disability (Annamma, Connor, & Ferri, 2013; Ben-Moshe, Nocella II, & Withers, 2013; Daniel Goodley & Runswick-Cole, 2016), Schalk marks the separation to represent her argument that disability and ability are not only mutually dependent but 'boundaries between disability and ability are uneven, contestable, and context dependent' (2017, p. 2). Whilst Kafer (2013) does not differentiate with a visual marker in writing, she proposes that disability can therefore be presented as an analytical category that presents both ends of a normative spectrum alongside gender, race, and sexuality. In this way, we move away from a binary and identity-based understanding of disabled/non-disabled and present disability as a contested and relational category (ibid), which opens possibilities for

interrogation of disability and activism within a context where the social model of disability falls short.

Schalk (2017) argues that using (dis)ability can help expand a CDS application to the critical study of power and oppression linked to bodyminds, which does not necessitate the presence of people with disabilities. She highlights how the broader system of (dis)ability affects all individuals, making it a valuable lens for examining broader social dynamics. However, other scholars have gone further, asking whether the uncoupling of disability from diagnosis can question who can 'claim' a disability identity, for example, by recognising that family members can 'experience' disability through proximity or discrimination (Guedes de Mello & Goyena, 2020; Kafer, 2013). Whilst I agree with the concept of discrimination by association, I think that it is inadequate to capture the complexity of experiences of people with disabilities and family caregivers, especially women and racialised people, for whom discrimination is not merely rooted in systemic oppression related to disability but in the interconnected nature of multiple systems.

As will be seen later in this thesis, capturing this complexity is particularly relevant in the case of mothers of children with disabilities in Brazil. As caregivers within a context of shrunken affordances, it is possible that beyond other experiences of oppression relating to race, social class and gender, they can also experience disability, albeit not necessarily in an embodied way. This can be experienced not only via proximity to their children, but via what Williamson et al. term as 'body-mind capacity-reducing nature of intensive home-based caregiving,' which poses it as *dis/abling*, or simultaneously enabling for children and disabling for mothers (2023, p. 473). The political/relational model, therefore, provides the space to interrogate how the depoliticisation of disability and care as private matters located within the family has implicated those responsibilised for unpaid care, primarily women and girls, in the realm of the disability category alongside people with disabilities.

2.3. Shrinking affordances: Experiences of disability and care in the peripheries

I introduce Dokumaci's theoretical work on *microactivist affordances* (2019), later redefined as *activist affordances* (2023), which builds on Alison Kafer's political/relational model (2013) of disability. Dokumaci's work applies Gibson's (1979) concept of affordances to critical disability studies. The theory of affordances (Gibson, 1979) comes from an ecological psychology studies perspective in which *affordance* is used to describe the possibilities for mutual interaction between an organism and its environment. In application to human organisms, environments *afford* certain bodyminds to do certain things, depending on the properties of the environment and the bodymind in question. Therefore, when an

affordance is absent from an environment-bodymind interaction, it restricts possibilities for action (ibid).

Dokumaci differentiates her concept of affordances from Gibson's by emphasising the *micro* and *activist* elements of her theory. Dokumaci's motivation for the theory of microactivist affordances comes from her desire for these small acts of resistance to be recognised and valued alongside other acts and actors more readily recognised as 'activist'. I note a parallel with the invisibilisation through depoliticisation of care work, uncaptured by the existing literature on parent experiences. The *micro* emphasises the ongoing and small nature of physical acts she refers to as 'creative workarounds, invent tools with existing materials, and author highly creative choreographies (for the "simplest" of daily tasks)', giving examples such as people with Rheumatoid Arthritis creating insoles for shoes, putton on a shirt in a way to avoid doing up buttons and using rubber to open bottle tops (Dokumaci, 2019, p.493). The activist element emphasises the enormous amount of activist labour required to create activist affordances where they are not easily perceived or readily available within the environment (Dokumaci, 2023). In the case of shoes, buttons or bottles, or any other human-made environment, the lack of readily available affordances results from their being designed for certain bodyminds, and almost always never for those that experience pain or do not move, react or perceive in normative ways. This highlights the applicability of the theory of affordances to disability.

Furthering Kafer's (2013) call to treat disability as an analytical category, Dokumaci suggests defining disability ecologically as 'the contraction of the environment and the inaccessibility, unavailability, or negation of its existing set of affordances' (2019, p. 495). She refers to this phenomenon as 'shrinkage', which she uses to expand the concept of disability beyond disabled bodies, or the contraction of 'space for action...ultimately the space for liveability afforded by the planet' (2023, p.95). Therefore, the affordability of opening a bottle shrinks when a bottle is not designed for opening with one hand, or with limited grip, for example. She also reflects on how shrinking can contract with changes to the body or the environment, and how bodies experiencing this can fall into the disability category, without impairment necessarily being present. For example, environmental degradation and changes can contribute to the shrinking of its affordances, or the possibilities that the environment affords for action for any organism. However, we know that not all organisms are equal nor impacted equally by shrinking affordances. I explore this concept further through the concept of debility.

Debility

Scholars have applied the concept of debility to the development of a political/relational model of disability to reimagine and trouble the disability category and ask, 'How are

incidents of illness and disability inextricably bound, and differentially bound, to race/class/gender/nation?' (Kafer, 2013, p.33). For example, Puar (2017) introduces "debility" as a state of bodily injury, harm and social exclusion that goes beyond previous definitions of disability. Puar highlights how states can actively produce debility in entire populations through targeted violence and political marginalisation, with impacts that are often slow, invisible, and depoliticised (ibid).

Drawing on Schalk and Kim's feminist-of-colour disability studies framework (2020), we can also conceptualise that shrinking affordances produces disablement and debilitation, particularly within racialised and other populations subjected to structural oppression, through state neglect, control and violence. Whilst disablement and debilitation are often used interchangeably, the temporality is different. Puar's (2017) use of debility understands it as a slower process of inflicting harm or wearing down, not necessarily just via injury to individuals. Debility can therefore impact whole populations through their political marginalisation and creation of structural oppression by state powers, as Puar (2017) demonstrates through the example of Israel's debilitation of the Palestinian population. In application to the Brazilian peripheries, we can consider the creation and maintenance of structural oppression as 'the planned absence of the state' (Instituto Update, 2018, p.29). Planned absence manifests in the lack of infrastructure, including healthcare, education and sanitation that typifies peripheral areas and contributes to the slow processes of harm.

On the other hand, disablement can be more instantaneous, referring to the creation of impairments through the societal and structural processes of disablement. Of course, disablement and debilitation are often linked: debilitation in the form of lack of or poor infrastructure can and frequently does lead to disablement, if not mortality. Under a political/relational model, we can, therefore, think of barriers to healthcare as part of structures that cause disablement alongside targeted violence, such as police targeting of Black and racialised communities. Schalk (2022, p.14) sees debility as a key component of Black disability politics, recognising the 'psychological, emotional, financial, and physical' impacts of the slow and continuous nature of racism that impact others beyond those who identify or are identified as 'disabled.' We see here how other systems of oppression are highly relevant in analysing disability in context and understanding how these contribute to the shrinking of affordances.

The concepts of disablement and debility therefore form key parts of the theoretical framework for this thesis, informing the understandings of disability as shrinking in the affordances present between people and the built or natural environment, but also in societal attitudes, system design and 'non-physical' elements of the environment. As Dokumaci puts it,

> *'disability occurs when the environment contracts and becomes affordance-less, no matter where that "less" comes from—whether it is a barrier, an ableist habitus, or the experience of chronic pain, disease, or debilitation.'* (2019, p. 511)

I argue that both disablement and debilitation play out within the physical environment of Brazil's peripheries: inaccessible and dangerous housing, flooding, environmental degradation, contamination, electrical blackouts, and lack of quality health services can all cause disablement (an instant event) or debilitation (an ongoing process of wearing down). Drawing on the work of other disability scholars who have previously linked these concepts (Puar, 2017; Dokumaci; 2023; Kafer, 2013), I will elaborate on debilitation through Nixon's (2011) concept of slow violence, showing how it can be applicable within context of the periphery, familial care and disability. However, I will first elaborate on how the concept of shrunken affordances captures the Brazilian context of the periphery.

The periphery as a site of shrunken affordances

I propose here that, in application to the Brazilian concept of 'the periphery', as outlined in the introduction, the concept of shrinking affordances that blurs the lines between body and environment can be helpful. Through the lens of shrinking affordances, we can think of the periphery as a 'site' of precarity and violence created by the state and the absence of state provision. I use 'site' not only as a geographic or identity marker but also to refer to the interaction between bodies and environments of those subject to the state's creation of structural oppression and the claimed political identity related to these experiences. Whilst Dokumaci uses 'shrunken environments' to describe places or situations that do not 'readily afford what people with a given disability need.' (2023, p.103), I suggest that this wording places too much emphasis on the spatial element, which does not reflect the Brazilian concept of 'periphery' that also claims a political identity based on lived experience, adopted in this thesis. Instead, I use *shrunken affordances.* Firstly, as already discussed, I focus on the state and permanence, rather than the process, of shrinkage (using the adjective form of the verb: *shrunken*). By stressing the state and permanence through the term *shrunken affordances* I do not mean to erase the wealth of knowledge and possibilities for action by suggesting an immutable state of being. On the contrary, I attempt to highlight the activist affordances of those living there despite the ongoing state of *shrunkeness* that is maintained in these environments and that those with peripheral identities have little choice but to navigate. Even if one leaves the periphery, one cannot always simply shed a peripheral identity. Secondly, *affordances* concentrate on the interactive nature of shrinking affordances *between* bodies and the environment and the relevance of intersecting systems of oppression that influence the peripheral identity. By considering the sociopolitical and historical context, we can see how the peripheries are both an environment and an identity

in which affordances - to healthcare, education and basic survival - have been contracted, restricted or shrunken to shape experiences of peripheral communities.

An intersectional lens is critical here; part of the analysis of the shrunken affordances in the periphery is a contextual reading of disability as a system of oppression, noting how it intersects with other systems of power and oppression (Schalk, 2017) in the study context. As mentioned earlier, an intersectional approach helps to move us away from the binary approaches of previous disability and activism research, which have limited applicability in the Global South, peripheral and other marginal contexts where affordances are constricted owing to systems of oppression. I acknowledge that in attempting to apply such a complex theoretical framework here, the risk is the failure to capture the complexity. However, I argue that an attempt to capture this is better than ignoring this complexity altogether, which forms part of the depoliticisation of disability by separating it from the other social systems with which it interacts.

This framework's novelty lies in applying Dokumaci's theory to the periphery and mothers of children with disabilities. I reiterate here that the experiences of mothers and their children are distinct yet inherently linked through the responsibilisation of care via familial care policies and being shaped by the periphery as a site of shrunken affordances. I also suggest that the concept of the periphery and microactivist affordances (Dokumaci, 2019) helps to provide a contextual understanding of intersectionality, which helps to shed light on experiences that are not traditionally represented in disability studies or activism. This will be further elaborated by applying the conceptual framework in analysing the study's empirical data, presented in Chapters Five, Six, and Seven.

Slow violence

The concepts outlined above – disablement and debility- have been elaborated through a lens of temporality, explaining how processes of slow and direct violence can play out in systems of oppression. Using these concepts, we can consider the impacts of shrinking affordances (Dokumaci, 2019) within the periphery as a type of slow violence (Nixon, 2011). As Dokumaci briefly touches on in her 2023 book, a political/relational definition of disability based on the idea of shrinking affordances links to Nixon's work on slow violence (2011), which is rooted in the study of temporal and ongoing impacts of chemical contamination on the environment. Whilst she does not interrogate these linkages further, she asks, 'where does this conceptualisation of disability fit with 'people whose lives are debilitated by slow violence'?' (Dokumaci, 2023, p.13). It is this question that I am interested in expanding to mothers of children with disabilities in the periphery.

A key feature of slow violence is its temporality, which allows distance between the causes and effects of violence (Nixon, 2011). We can use this distance to consider how slow

violence might apply to the debilitation of mothers and children through familial care within a context of shrunken affordances, which would not be conceptualised as a form of violence. In these contexts, via familist disability policy, support and care are usually assumed via the unpaid labour of women's family members – most notably spouses and, in the case of children, mothers, which is the object of this study. However, I highlight that in non-peripheral contexts this work is assumed using low-paid labour of Black and migrant women who are also subject to intersecting systems of oppression and might therefore be subjected to the disabling and debilitating nature of such work and environments. Williamson et al. explain that a combination of inadequate care policies, gendered care roles and colonial history of employing poor Black women to care unpaid or for minimal remuneration produces dis/ablement, meaning 'it is not just people with illnesses or injuries who experience disability, but also the caregivers, their networks, and homes too.' (2023, p.474). Here, the political/relational model of disability allows us to look more broadly at the context in which debilitation intersects with disability because of the shrinking affordances dictated by the sociopolitical and historical context.

As noted earlier, framings of dis/ablement and debilitation have been applied in the context of chronic, home-based caregiving in Brazil and also draw on the concept of slow violence (Williamson et al., 2023). However, like Dokumaci, the concept of slow violence is yet to be applied to mothers of children with disabilities in the periphery. In this location of dis/ablement, the focus of this study is on the human interactions between mother and child within the peripheries and how these interactions simultaneously create possibilities for the child, yet can reduce possibilities for the mother. This includes the consideration that the act of care and affordance creation without adequate support can produce impairment through the process of debilitating bodyminds.

I stress that the act of care is not always disabling or debilitating but becomes so in a context of slow violence (Nixon, 2011), whereby the state neglects to provide adequate support through reliance on familial care policies and poor or absent infrastructure. I ask, for example, at what point does raising a child with disabilities as a solo caregiver, without enough financial resources and constant battling for survival and access to fundamental rights, become so stressful that it counts as debilitation? This brings us to the key objective of this theory as employed in this study, which is to help explain the constriction in the periphery experienced by children with disabilities and those responsible for their care and support in the absence of the state.

2.3.1. (Micro)activist affordances and people as affordances

To reiterate, applying the concept of affordances to disability focuses attention on the *interaction* between a body and its environment (Dokumaci, 2019; Gibson, 1979). This

approach, whilst not a complete departure from the social model, is more appropriate in its application to the study of activism, since the social model tends to focus on the barriers present in the environment and therefore erases the autonomy and actions of individuals (Gabel & Peters, 2004), as outlined earlier.

In applying the theory of affordances, we can, therefore, reveal how people respond and react to their environment's shrinking affordances (Dokumaci, 2023), or what I refer to as a site of shrunken affordances, to stress the more permanent state of being, as described earlier. Dokumaci (2019) terms this *microactivist affordances*. Although she later refers to the same concept as *activist affordances* (2023), the micro element, as discussed earlier, remains. This element, I argue, is relevant for application to the actions of mothers at the individual level, meaning, relating to their children and lives.

However, I highlight here that Dokumaci's theory is based on physical acts of affordance creation by people with Rheumatoid Arthritis, whose bodily interactions with their environments she photographs and films, catching the 'tiny, modest and humble' (2023, p.104) characteristics of actions. Through my thesis, I play with applying microactivist affordances to a broader context. Rather than focusing on stiff joints doing up zippers, I ask what the usefulness of microactivist affordances is in the analysis of the invisible everyday struggles of mothers of children with disabilities at the individual level, as they create affordances within their homes, at school, and in healthcare settings, and in their own families? Can affordances be made for healthcare and education, and what do those acts look like? What is revealed when we apply this theory to ongoing actions that aim to develop affordances to a system or service, like healthcare, education or social assistance?

Whilst Dokumaci's work is mainly applied to physical acts of affordance creation by people with arthritis, I propose it as a robust framework to be able to link together both the constraints placed on families by intersecting systems of oppression and their reactions and resistance to these constraints, in a way that other readings of disability and activism do not.

The periphery as a site of microactivist affordances

Crucially, the theory of microactivist affordances draws on the work of Alison Kafer (2013), to recognise that shrunken affordances also provide 'generative potential to emerge from constraints' (Dokumaci, 2019, p. 492). I note here the parallels with the work of other feminists and postcolonial scholars, including Black feminist work on feminist standpoint theory. For example, bell hooks (1989, p.20) work on the politics of location argues that the margins are more than just a site of oppression but are also a site of change, knowledge production, resistance and 'radical possibility.' Essentially, the perspective that the

periphery as a site of shrunken affordances informs the ability to resist in various ways that may not be captured by existing activist theories.

It may be helpful to see this resistance through the lens of microactivist affordances, which offer opportunities to develop creative solutions to a lack of available affordances that constitute repeated and ongoing 'performances' that build new habitable worlds, or environments that welcome and cater for people with disabilities (Garland-Thompson, 2015; Dokumaci, 2019). This is particularly relevant in its application to the periphery because it reflects the duality of the periphery, as outlined in the introduction, that supports hooks' theory. In other words, besides being conceptualised as a site of shrunken affordances, we can also see the periphery as a site of varying forms of resistance through knowledge production and collective development of creative alternative solutions via affordance creation.

I also propose, therefore, that affordance creation, as well as taking place on a micro scale at the individual level, can and does take place at the peer or community level, and even at the systems level, which I explore more in the following subsections. Here, I draw on research done in the peripheries with peripheral co-researchers. Through their collaborative research project investigating community networks in Brazil's peripheries, Pereira et al. (2018, p.21) write,

> *People come together around themes of interest, sometimes temporarily, and begin to investigate, produce knowledge or take action based on this collective identity…In the collectives and networks, new possibilities for the emerging politics are constructed.'*

Although, as I understand it, Dokumaci's theory does not, and is not meant to be applied to organised forms of activism that are more readily recognised. However, I propose that, in the context of the periphery and this study, organic forms of microactivism are connected to more organised forms of activism that aim for system-level change. I demonstrate this by developing the concept of (macro)activism, highlighting its linkage to mothers' everyday, microactivist actions at the individual level and their exchanges via mothers' networks. This framework aims, therefore, to trouble the categories of disability and activism through expanding a critical disability theory of microactivist affordances, which makes visible the everyday actions and emerging politics of the periphery that constitute affordance creation within sites of shrunken affordances.

Mothers as affordances

In the context of this thesis, how does the concept of microactivist affordances illuminate the experiences and actions of mothers as they navigate the shrinking affordances, which primarily affect their children but also impact themselves? Dokumaci's later work expands on microactivist affordances by drawing on the work of Mia Mingus around access intimacy (2011). Access intimacy refers to when access needs - physical, emotional or structural - are understood and spontaneously met by another person. Applying the theory of microactivist affordances, Dokumaci terms this 'people as affordances': when affordance creation is enacted by one person for another, whilst pointing out that people as affordances might also fail to materialise and that people can also be barriers to affordances (2020). Mothers can then act, or fail to act, as the affordances by which children interact with their environments – interactions that would not otherwise be realised in a context of shrunken affordances.

For our context, the most relevant example that Dokumaci (2020) presents is the example of a child being carried to school by his father each day, in the absence of transport, road infrastructure or a wheelchair presenting alternative affordances to travel. This is equally relevant for the Brazilian context, where lack of infrastructure, as described earlier, contributes to shrunken affordances of the periphery. However, as well as these acts - or performances, as Dokumaci (2019) terms it - I am also interested in the administrative and dialogical affordance creation that mothers are often tasked with, but are rarely acknowledged. These performances might take the form of repeated phone calls, voice messages or internet searches for self-education on a child's diagnosis, arguing with a professional, or exchanging voice messages with other mothers to pass on valuable information. These performances, between people to create affordances for others, capture the nature of reciprocal relationships, which tie bodies to each other and communities (Erevelles, 2011). This framing is helpful because, as outlined in the literature review, the everyday interventions of mothers are often not understood to be political, broadly because disability is not understood to be political nor relational and therefore their performances are not understood as activism.

Microactivist mothers as activists

As Dokumaci (2019) points out, microactivist performances are not necessarily recognised as disability activism, and people engaging in these performances may not identify as disabled. By conceptualising actions by mothers as people enacting microactivist affordances in building disability worlds of possibility for their children, or what Dokumaci terms bringing 'accessible futures' to life' (2023, p.203) in a context of shrinking affordances, it allows us to politicise and make visible the interventions of mothers on behalf of their children that go beyond typical mothering and beyond physical acts of affordance creation. Creating affordances can therefore also capture elements of Douglas's (2016) notion of

radical pedagogic care, and Rapp and Ginsburg's (2011) concept of 'new kinship imaginary'. This idea is where mothers engage in pedagogical exercises to transform or reevaluate understandings of disability and normality and reimagine relationships with their child based on non-normative frameworks while encouraging others to do so. I will therefore attempt to expand Dokumaci's framework, which is developed for application at the individual level, to analyse how mothers' actions work at the peer and systems level towards change.

Drawing again on Kafer's political/relational model (2013), I propose here that Dokumaci's theory of microactivist affordances (2019) and people as affordances 2020) to study care and disability can be enriched by further engagement with an intersectional framework. Whilst Dokumaci's theory of *people as affordances* (2020) sheds light on the relationships between people and how this can lead to microactivist affordances being enacted between bodies, the concept fails to analyse *which* bodies and systems are at play here, beyond looking explicitly at disability. Although in later work, she engages with critical race theory in the elaboration of her theory of 'shrinking', including noting that this concept supports the call for CDS scholars to take a more intersectional approach and move away from viewing disability as an identity category (Dokumaci, 2023, p.90-91), she falls short of extending this to the theory of *people as affordances*. Whilst Dokumaci's framework lends itself well to an intersectional analysis, *people as affordances*, does not in its application thus far, provide explicit analysis beyond disability to tease out how this is connected with other identities and related systems of oppression, for example, at the nexus of care work.

An expanded intersectional application is essential within the context of this thesis to politicise the gendered and racialised nature of microactivist affordance building in care work by further interrogating which groups of people must enact microactivist performances to ensure their own or another's survival in a context of shrinking affordances. Nirmala Erevelles highlights this importance, pointing out,

> *'the marginal discourse of disability and the caring work associated with it is not, in fact, something that is peripheral to our social order. Instead, it marks the point at which the relations of capital, class, caste, race, gender and disability intersect, and it should therefore be the place where we begin and not end our analysis of modern society*' (2010, p. 535).

Disability in this way becomes central to an intersectional framework.

At the same time, disability and issues of care work have been mainly excluded from intersectional analyses or included in isolation from each other as an 'add-on', rather than taking a central location from which different systems of oppression can be understood. Indeed, many Black, Indigenous, People of Colour and Disabled scholars and activists from

the US have pointed out that disability and race are deeply entwined through their use to mark Black and other racially marginalised populations as different and physically, morally or intellectually inferior (Bailey & Mobley, 2019; Sins Invalid, 2017; Lewis, 2021; Schalk, 2017; Schalk & Kim, 2020; Schalk, 2022). To abide by the CDS principles outlined earlier, we must, therefore, contextualise disability by asking which people with disabilities and which communities are subject to environments of shrinking affordances, that imposes the necessity of microactivist affordances (Dokumaci, 2023), and why. Which policies and actions of the state contribute to shrinking affordances, resulting in slow violence in the peripheries? Who is debilitated by this slow violence? Which family members are made responsible for creating affordances as part of a depoliticised 'care' role? Which affordances are created, and in the interests of whom?

By asking and attempting to answer these difficult questions, which are located in the tensions of multiple theoretical approaches, I have aimed to produce a conceptual framework that helps to advance theory beyond the field of disability studies, yet retains disability at the centre. In the context of this study, these tensions include but are not limited to the following four observations. Firstly, 'the contested place of mothering in critical disability studies', where perspectives of mothers of children with disabilities remain marginalised (Douglas et al., 2021, p. 2). Secondly, the tensions between a Western-centric disability framework and the disablement of communities in the Global South through deprivation of resources, exploitation and exploration (Puar, 2017; Meekosha, 2011; Erevelles, 2011). Third, the reduction of disability to a medical phenomenon by governments, scholars, and civil society actors resulted in the removal of disability from radical politics and social movements (Kafer, 2013). And finally, tensions between parents and disability rights activists (A. Carey et al., 2020; A. C. Carey et al., 2019; Groce, 1996; Naples, 2013; Panitch, 2008). Only by delving into these tensions can we further the debates around disability, care, activism and social justice.

Finally, by applying to the case of Brazil the lens of mothers as (micro)activist affordances at the family level and the building of microactivist networks at the community level, which is done in Chapter 8, we are able to focus on mothers' actions and what they afford rather than what is or is not already theorised under traditional understandings of activism. I aim to expand Dokumaci's statement,

> *'If we define activism not by who engages in it, where and how, but by what activism does and what it affords, then disorienting buttons, twisting bottles, and transforming shirts into pullovers can also count as activism'* (2019, p. 516)

by asking what else can count as activism? How might looking at mothers' actions, in particular, help advance understandings of disability activism?

2.4. Chapter Summary

This chapter has restated the gaps presented in the literature review and proposed a conceptual framework that aims to address those gaps. Following the argument of Sami Schalk (2022) that Western frameworks for understanding disability applied in racialised and marginalised communities are inadequate at explaining how disability politics arises in these settings, I presented a conceptual framework that aims to historically and contextually situate disability and activism experiences. In summary, the conceptual framework for this project takes a broad Critical Disability Studies approach, drawing on Kafer's (2013) political/relational model of disability, to apply an intersectional feminist Critical Disability Studies lens to the problem of the experiences and actions of mothers of children with disabilities and to interrogate disability activism. It proposes Dokumaci's theory of microactivist affordances (2019) as a way of theorising mothers' actions and politicising mothering within a peripheral context.

Using the Brazilian concept of the periphery, which goes beyond a spatial understanding, as outlined in the introduction, helps to develop the theory of shrunken affordances, as it provides a contextual understanding from an intersectional perspective that reveals the overlapping systems of oppression shaping the experiences and actions of mothers of children with disabilities in the periphery. In response to the arguments of CDS scholars discussed in this chapter that disability cannot be understood without analysing it within context, including the creation of impairments and how disability is experienced at the intersection of multiple systems of oppression in marginalised contexts (Chaudhry, 2019; Hall, 2019; Kafer, 2013; Schalk, 2022), the following chapter aims to contextualise disability and activism within historical and present day Brazil.

Chapter 3 – Locating disability, familism & activism in Brazil

3.1. Introduction

The previous chapter reviewed the gaps identified in the literature and introduced a conceptual framework for the study. This framework adopts a broad Critical Disability Studies perspective, drawing on Allison Kafer's (2013) political/relational model of disability and applying an intersectional feminist lens to the experiences and activism of mothers of children with disabilities in Brazil. Additionally, the framework applies Dokumaci's (2019) theory of microactivist affordances to theorise and politicise mothers' actions, particularly within a peripheral context. The framework sets the stage for the current chapter, which builds on this framework to provide further background on the complex dynamics of disability, familism and disability activism in Brazil.

This chapter contextualises disability, care and activism in Brazil, giving a historical and political background to the present policy and sociocultural landscape that impacts children with disabilities and their families. Such a contextualisation is necessary since this study's theoretical approach understands that impairment and disability are both social. Since impairments are also socially understood and created, disability must be politically and historically contextualised (Kafer, 2013). I aim not to give a complete and comprehensive historical or political account of Brazil, but instead an overview of relevant key points in the country's history that have helped to shape disability and care policies and norms. I then aim to analyse these through an intersectional relational/political model of disability, as presented in the previous chapter.

I begin with an overview of Brazilian history in relation to disability and activism, starting with an analysis of the impacts of colonisation and slavery on motherhood and disability. This is followed by an overview of disability and activism from the era of the first Republic at the end of the 19th Century through the period of democratisation at the end of the 20th Century. I present an analysis of early and later disability activism in the country in the 21st Century, including responses to 21st-century health emergencies. The second section provides an analysis of Brazil's most pertinent persisting inequalities in relation to this study, including modern slavery, health inequity and environmental racism, issues with disability diagnosis and classification, social support for children with disabilities and their families, institutionalisation and care work.

3.2. Locating disability and activism in Brazil's history

This section locates disability and related activism within Brazil's history. I start with a brief look at the country's colonial history, moving on to the period of the military dictatorship between 1964 and 1985, followed by the subsequent period of democracy and development in which Brazil's Constitution was drafted, a document which set the stage for modern disability activism. Then, I will move on to the formation of the Unified Health System (SUS), the national level public health system, and the psychiatric reform, a major reform of psychiatric care and an ongoing movement to end institutionalization, analysing how these shaped conceptualisations of disability in the country, before ending the section with an overview of disability activism in 21st Century Brazil.

3.2.1. Legacies of colonisation and slavery on motherhood and disability

Taking a relational/political approach (Kafer, 2013) to studying disability in Brazil means a current-day analysis cannot be separated from the country's history. Scholars generally divide this into the pre-Cabraline[3] period, until 1500, followed by the colonial period, from 1500 to 1822, imperial, from 1822 to 1889 and republican, from 1889 until the present (Fausto & Fausto, 1994; Pimentel et al., 2023; Prous, 2006). For the purposes of this analysis, I will not include the pre-1500 period, since very little is documented about this time, and it is beyond the confines of the study to do it justice. Furthermore, I will not separately analyse the colonial and imperial eras, which together encompass the centuries of colonisation by the Portuguese and other European powers and involvement in the enslavement and trafficking of Africans to the territory from 1540 until the practice was officially made illegal in 1888.

I point out here that most existing disability research undertaken in Brazil does not mention how these processes and their ongoing legacies continue to shape conceptualisations of disability and the production of disabled bodies. Besides a few exceptions to be discussed (Lobo, 2008; Oliveira, 2023), few historical accounts of slavery in Brazil apply a disability analysis or acknowledge the central role of disability. Bruna Oliveira (2023) suggests that this is a combination of the lack of importance given to disability, differences of the category of disability at the time and a reflection of the current modern day exclusion of people with disabilities from the labour market, based on ableist assumptions of unproductivity, contributing to the assumption that they were simply excluded from the slavery system. Support for this theory comes from Romeu Sassaki (2003), who notes that people with disabilities were broadly referred to as *'os inválidos'* [EN: invalids] during this period, reflecting one societal view of this group as useless and a burden. This wording has also

[3] Named after Pedro Álvares Cabral, who is generally considered as the first European to travel to Brazil.

perhaps added to the obscuring of experiences of enslaved people with disabilities, exacerbated by a lack of analysis of the nuances of the category by scholars.

Lilia Ferreira Lobo is one of the only Brazilian historians to focus on the obscured and silenced histories of those considered 'invalids' and 'incapable' in her groundbreaking book, 'Os infames da história: Pobres, escravos e deficientes no Brasil' [*EN: The infamous of history: Poor, slaves and disabled in Brazil*]. She argues that understanding the subjectification of indigenous and Black people, people with disabilities, unemployed people and children to extreme forms of marginalisation, control, and repression by the Crown, Church, feudal lords and now by the government is central, rather than peripheral to Brazilian history and its persisting social inequalities (Lobo, 2008). By looking again at historical records from Brazil and other places involved in the transatlantic slave trade, notably the antebellum South of the United States, we can build a more accurate picture of the historical relationship between disability and enslavement from which to draw insights.

Despite the lack of historical analysis of disability in relation to the slavery system, there is historical evidence showing not only that people with disabilities were enslaved but that ranking the value of enslaved bodies was a key element of the slavery system. For example, sale records in Brazil show that prices of enslaved persons could be dependent on age, gender, ethnicity, colour, body type, and other bodily characteristics[4]. Analysis of accounting records in Brazil shows enslaved people frequently becoming disabled or contracting illness and disease because of poor living conditions and violent punishment by enslavers, and therefore 'depreciating' in value (Monteiro & Melo, 2023; Lemos et al., 2020; Silva, 2014). Through a Critical Disability Studies framing (to be presented in the following chapter), I read the depreciation of enslaved peoples as debilitation via disablement and maiming and disability as integral to the categorisation, dehumanisation and (de)valuation of enslaved bodies. However, whilst topics such as depreciation, categorisation and dehumanisation are frequently discussed in the literature on slavery, they are rarely linked to documentation of the experience of enslaved people with disabilities or discussed *vis-à-vis* disability.

There is some evidence to suggest that 'depreciation' due to disability, sickness or old age led to the freeing of enslaved people (Lemos et al., 2020). However, disability did not necessarily exclude people with disabilities from the enslaved labour force. For example, a study of the sale and advertisement records of enslaved people in Brazil in 1871 found that blind people were included and, in some cases, preferred because of their productivity for certain tasks and the increased control that could be exerted over them by enslavers (Oliveira, 2023). By applying a relational/political model of disability, we can draw comparisons between Schalk's definition of (dis)ability as a system that ranks and values bodyminds based on socially constructed ideas of ability and disability (2017), and the logic

[4] Based on my own observations during a field visit to gold mines in Ouro Preto, Minas Gerais, May 2022.

used to define worth and depreciation within the system of slavery and emancipation. The practice of ranking and categorising bodies in relation to their productivity was central to the slave system, which places the (dis)ability system at the centre of Brazil's history rather than at the margins, as the literature would suggest. Furthermore, it points to how the slave system influenced conceptualisations of disability as linked to the body and productivity, that is deeply rooted in eugenics, racism and colonisation.

There is limited documentation on enslaved people with disabilities and mothers of children with disabilities in Brazil to contextualize the experiences of Black and racialised women today in relation to disability, motherhood, and care work. However, research from the US Antebellum South may offer insights, given both countries' roles in the Transatlantic slave trade and the exploitation of enslaved Africans for cash crop production. Jenifer Barclay (2014), for example, highlights how enslaved women's forced labour often compromised their ability to care for their families, especially children with disabilities, who were often deemed 'useless' by enslavers. Yet, mothers resisted these dehumanising views through acts such as seeking medical care, avoiding family separation, and building care networks with other enslaved people with disabilities. Similarly, Reis (1993) describes how enslaved women in Brazil engaged in subtle, everyday forms of resistance alongside more visible acts like rebellion and escape. These forms of 'daily resistance' likely encompassed the strategies Barclay describes, many of which went undocumented or unrecognised as resistance.

Even less is known or documented about Indigenous approaches to disability and how these have been influenced over centuries of colonisation of Indigenous territories and the systemic erasure of Indigenous peoples in Brazil. Araújo (2014) writes that racist stereotyping ideas that Indigenous people with disabilities do not exist because of widespread practices of infanticide have been prevalent since the 16th Century and endure today. However, there is overwhelming evidence that colonisation, land dispossession, loss of traditional livelihoods and persisting structural racism have resulted in detrimental impacts on the physical and spiritual health and wellbeing of Indigenous peoples in Brazil (Cardoso, Tavares, & Werneck, 2022; Rebouças et al., 2022). However, such fallacies as the one pointed out by Araújo perpetuate in Brazilian society, reflected in and supported by the systematic erasure of Indigenous people with disabilities in most of the disability discourse in Brazil that continues today. This erasure, along with the further detail about health inequalities experienced by Indigenous people and people with disabilities, will be explored in the later section on persisting inequity.

3.2.2. The Brazilian Republic – end of the 19th Century

As modern-day Brazil emerged towards the end of the 19th Century, Black and Indigenous people, women and people with disabilities continued to be excluded through the ranking

system that placed them outside of the sphere of citizenship based on racist, ableist and sexist ideologies. Following Brazil's independence from Portugal in 1822, Brazil's first 1824 constitution, proposed by Emperor Pedro I laid out the conditions for citizenship, excluding women, enslaved people and defining ineligibility of citizenship and political rights on grounds of 'physical or moral incapacity' (BRAZIL, 1824). External influence from Europe during this period also led to initiatives for the education of Deaf and blind people, and the establishment of educational institutes designated to these populations, respectively (Moises & Stockmann, 2020). These historical exclusions and the marginalisation of Black and Indigenous people, women, and people with disabilities laid the foundation for enduring inequalities in Brazil, whose effects continue to shape the social, political, and economic landscape today.

Brazil was the last country to officially abolish slavery in 1888, though it is critical to understand that this did not lead to the emancipation of former enslaved people or their descendants, who continued to be denied access to land, education and employment opportunities. Large-scale migration of formerly enslaved people to urban areas during this period was followed by urban development initiatives that cleared out urban centres and pushed this population to the edges of cities, whereby illegal settlements or favelas [EN: slums] were established, often in hilly and inaccessible areas (Magalhães, 2010). The informality of these settlements defined their precarity, with poor sanitation and infrastructure. However, this process of peripheral urbanisation, which includes *autoconstrução* [EN: autoconstruction] of the urban peripheries, turned them into 'a space of alternative futures' (Holston, 2021, p.8) whereby citizens who were denied rights based on their membership of certain social categories also resisted. The peripheral urbanisation, went beyond physical construction during this period and led to construction of diverse social movements that reflected the complexity of social and cultural dynamics that still persist today.

The promulgation of various policies at the end of the 19th and beginning of the 20th Centuries during the early Republican period also further institutionalised racism and ableism. For example, miscegenation, immigration and eugenic policies during the period between 1918 and the 1940s aimed to promote marriages between specific populations, namely of white migrants, and discouragement of 'non-human unions' that were considered harmful to society, such as Black people and people with disabilities (French & Stepan, 1993; Schwarcz, 1993). Lobo (2008) writes that the practice of eugenics, linked to the Hygienist movement, focusing on sanitation and public health with the aims of societal reform, led to sterilisation and education of 'idiots' through normalisation processes via segregated educational institutions for 'abnormal' and 'normal' children. These historical practices and policies continue to shape the systemic exclusion and marginalisation of these communities, for example, through a segregated school system, perpetuating cycles of inequality that are still deeply entrenched in Brazilian society today.

It was around the time of the first Republic of Brazil, declared in 1889, that Kardecist Spiritism started to gain popularity in Brazil, having arrived from France at the end of the 19th Century. In Kardecist spiritism, based on the works of Allan Kardec, conceptualisation of mental illness takes a biopsychosocial approach in that it notes a combination of internal and external environmental factors, but also a spiritual element, noting the influence of 'disincarnated spirits' and experience in past lives; Moreira-Almeida & Koss-Chioino term this approach a 'bio-psycho-socio-spiritual' model (2009, p. 272). Therefore, spiritist approaches to the body and healing are based on a mind-body approach that contrasts with Western biomedical and binary approaches to the body as separate from the mind and aligns more closely with Price's (2015) concept of 'bodyminds', as introduced in Chapter Three. Greenfield (2004) suggests that this approach to healing, using the example of disobsession rituals, integrates biological, psychological and sociocultural dimensions. Indeed, as will be explored shortly, spiritist approaches to healing have been widely incorporated into modern psychiatric treatments.

It is also noteworthy that African traditions imported through the Transatlantic slave trade mixed with European belief systems to form Afro-Brazilian traditional religions. For example, African beliefs were influenced by Christianity to create Candomblé and other variations and separately with Spiritism to create Umbanda (ibid). These Afro-Brazilian traditional religions are still popular in Brazil today, even regaining popularity despite demonisation from the Evangelical church and the State, which manifests as a form of religious racism (Cerqueira & Obalerá, 2024). They therefore likely continue to shape modern conceptualisations of the bodymind and disability. However, it is beyond the scope of this study to go into further detail about the conceptualisations of disability across the different Afro-Brazilian traditional religions. I therefore leave this analysis here as these have likely had less influence on how disability is conceptualised within mainstream institutions than spiritism. But I reiterate the importance of taking a nuanced approach as far as possible to the social, cultural, religious and political histories that shape ideas around bodies and illness and that this is an area for further research, especially in communities where these religions are widely practised.

3.2.3. Early 'disability movements'

Early disability movements in Brazil emerged in the late 19th and early 20th centuries, largely driven by a growing awareness of the rights and needs of people with disabilities. These changes were linked to the development of social and working class movements, labour and women's rights under the 1934 constitution and the Hygienist and New Education movements (Moises & Stockmann, 2020). However, these initiatives were distinctly separate from the later movements led by people with disabilities – hence the use of quotation marks in the subheading - and dominated by medical, charity and eugenics

approaches rather than a focus on rights and inclusion. People with disabilities during this period were referred to as 'os incapacitados' [EN: the incapacitated], and later, *'os defeituosos'* [EN: the defective] and *'os deficientes'* [EN: the deficient] (Sassaki, 2003), which made little progress in terms of earlier language, and still focussed on lack of capacity. These movements saw education and medicine as important for a healthy society and established normative approaches that linked education to biological capacity and reinforced a system of meritocracy that marginalised people with disabilities (ibid). However, they were the first movements that recognised people with disabilities as a group entitled to rights, which led to waves of significant change and, as such, are worth including in this analysis.

In Brazil, much like in the US and elsewhere, parents of children with disabilities played a significant role in the early initiatives for people with disabilities, driven by a lack of state support. In 1954, the Associações de Pais e Amigos de Pessoas Excepcionais (APAE) formed, started by a mother of a daughter with intellectual disabilities, and chapters spread over Brazil until there were 1,600 APAE branches by the end of the 20th Century (Block & Cavalcante, 2014; Cavalcante, 2003). APAEs along with the Pestalozzi Centres[5] are observed as being part of a group of philanthropic organisations that dominate the sector in providing assistance and services, including health and education, to families with children with disabilities, largely taking a charity-based (Nunes, 2014) and, I add, primarily a medical approach, albeit with many positive outcomes for families and their children, who would otherwise remain isolated and unsupported. Besides influencing service provision and policy, these organisations have shaped modern-day understandings and language around disability in Brazil, owing to their visibility and philanthropic nature. Scholars note that the terms 'special' and 'exceptional' were proliferated by parent organisations like APAE to describe people and children with intellectual and psychosocial disabilities (Lopes, 2019; Sassaki, 2003), terms which organisations of people with disabilities and rights-based social movements later rejected. Furthermore, I highlight that these organisations continued to be successful in Brazil because of the absence of state support for the populations they serve (Cavalcante, 2003), although some of them have shifted their approaches to be more aligned with the rights-based approach that reflects Brazilian disability law.

It is widely agreed in Disability Studies and activism, internationally and in Brazil, that there is an important distinction between organisations *for* and organisations *of* people with disabilities (Kirakosyan, 2016; Silva & Oliver, 2019). In Brazil, during this period, some organisations *of* different impairment groups were started by beneficiaries and patients of the large philanthropic organisations that dominated during this period (Silva, 2012).

[5] According to the website of the National Federation of Pestalozzi Associations of Brazil, 'the Pestalozziano Movement is the first organisaed movement in Brazil in the area of people with intellectual and multiple disabilities. It currently has 185 Civil Society Organizations present in all regions of the country [working] to ensure the defense and guarantee of rights and the provision of specialized services in the areas of Social Assistance, Health, Education, Work, Sports, Culture, Leisure, Science, Technology and Innovation.' (FenaPestalozzi, 2025).

However, the broader mobilisation of people with disabilities towards a rights-based agenda occurred later alongside Brazil's democratisation process. Crespo (2009) maintains that although there had been organisations of people with disabilities since the 1950s in Brazil, there was no move beyond single-impairment interests towards a more unified movement that spoke for themselves and pushed back on religious and philanthropic approaches until 1979. It was during this period that people with disabilities began to take a role in social control, closely linked to the development of other social movements – including the Black, women's, gay rights and workers movements that took place alongside the democratisation processes (Crespo, 2009; Silva & Oliver, 2019). I now turn to this period to discuss its influence on later disability activism in the 21st Century.

3.2.4. Development and democracy

Brazil's military dictatorship lasted between 1964 and 1985 and marked a period of extreme oppression, human rights abuses and persecution of those speaking out against the regime, including many intellectuals, activists and civil society leaders. As a result, prior to the democratisation processes of the 1980s, disability activism faced significant challenges, and there was more of a focus on rehabilitation and special education. For example, institutions were set up by medical professionals with the object of rehabilitating children with disabilities rather than focusing on changing wider education systems to support their inclusion (Sassaki, in Crespo, 2009), such as the philanthropic institutions assisting children with disabilities and their families as discussed above. Whilst I would argue that this still promoted a medical approach to disability, Pletsch (2010) notes that there was a slight shift towards an educational approach during this time, which aimed to prepare citizens for a modern capitalist society and war. It is possible that the rehabilitative and educational approaches built on the medicalised approach to disability were also influenced by the Hygienist Movement's aim towards improving society. Supporting a broader depoliticalization of disability, this approach was likely not seen as a significant threat to the military authorities.

The international disability movement also influenced the development of disability rights movements in Brazil. Indeed, According to Brégain (2013), peaceful street processions employed by disability rights activists in Brazil started with one in 1980 and increased to fourteen the following year - the International Year for People with Disabilities, as noted by Kirakosyan (2016), was a key event that significantly influenced the mobilisation of disability activists nationally. It was during this period that disability activism gained more visibility and began to influence policy change, culminating in the 1994 creation of the Brazilian Association of People with Disabilities (ABCD) and other rights-focussed organisations and the passage of the 1988 Constitution, which recognized the rights of people with disabilities thanks to the work of disability rights activists. In 1999, after over a decade of sustained and

coordinated effort from the disability rights movement, *Conselho Nacional de Direitos das Pessoas com Deficiência* (CONADE) [EN: the National Council for the Rights of Persons with Disabilities] was created within the Ministry of Justice, which further institutionalised organisations of people with disabilities into decision-making processes, albeit alongside some of the existing philanthropic and parent-led organisations, who did not take a wholly social model approach.

The medicalisation of disability through a focus on rehabilitation was supported by many parents during this time, influenced by the severe lack of state support and the influence of modern medicine. Between the 1980s and early 1990s, families came together in their homes to exchange experiences and develop proposals to present to government agencies, particularly concerning the expansion of healthcare and education for their disabled children (A. C. C. da Silva & Oliver, 2019). In some cases, this led to the formation of parent-led organisations, as demonstrated in the case of parents of Autistic children, who, in 1983, founded Associação de Amigos do Autista (Association of Friends of Autistics—AMA) in São Paulo (Rios & Andrada, 2015). As noted in Chapter One, families of Autistic children leading advocacy in the 70s and 80s were primarily middle-class and, therefore, most likely, majority white (Block & Cavalcante, 2014; Brégain, 2013). According to Block and Cavalcante (2012), parent and medical professional-led groups imported models and approaches to activism from Europe and the US that focused on rehabilitation and treatment. This is interesting because it helps explain why parents led the development of services for Autistic people, as well as setting the agenda for scientific research with professionals in a way that hadn't previously been done in the 1950s with APAE (Block & Cavalcante, 2014). It is likely, therefore, that the involvement of parents who had significant social capital to use in their pursuit of a scientific agenda was tied in some ways to the continued medicalisation of disability, which was institutionalised through the public health system as discussed in the next section.

3.2.5. Redemocratisation and the Health Reform

The country's transition to democracy during the 1980s saw landmark political and social reforms for healthcare, urban planning, social security and education, rights that were guaranteed by the new constitution. The Constitution also explicitly guaranteed rights and protections of Indigenous peoples, people with disabilities and protection on grounds of race/colour, sex, age and other grounds (Brazil, 1988), which was fundamental in addressing racial discrimination and paved the way for more progressive policies. The creation of a coordination unit for disability inclusion within the government in 1986 was also a significant response to the lobbying of Brazilian civil society; the *Coordenadoria Nacional para Integração da Pessoa Portadora de Deficiência (CORDE)* [EN: National Coordination for

the Integration of People with Disabilities], as the first institutionalised mechanism to ensure equality and inclusion of people with disabilities as citizens.

The *Sistema Único de Saúde (SUS)***,** Brazil's Unified Health System, was established in 1988 as part of the country's transition to democracy and underlined the right to health for people with disabilities. Under the SUS and the new constitution, universal access to health was established as a right of all citizens alongside principles of equity and comprehensiveness (Brazil, 1988; Ministry of Health, 2005). The SUS was complemented some years later by the Sistema Único de Assistência Social (SUAS) [EN: Unified Social Assistance System, established as Brazil's national policy framework for social assistance in 2005 to streamline the country's social assistance services for vulnerable populations. These progressive new systems, supported by the 1988 Constitution, played a pivotal role in shifting Brazil towards a more inclusive society, formally recognising the rights of previously marginalised populations, and setting the stage for more progressive policies.

Redemocratisation efforts during the 1970s and 80s also brought about rights-based approaches to psychiatry when mental health care workers formed the *Movimento Anti-manicomial* (En: anti-asylum movement) (Block & Cavalcante, 2014). This social movement eventually brought about the psychiatric reform in Brazil, which began in the late 20th century alongside similar changes in different countries. It aimed to shift from a model of institutionalisation to a more inclusive, community-based approach for mental health care in policy. Prior to the reform, people with psychosocial disabilities and mental health conditions were subject to what João Biehl described as 'animalization' (2001, p. 133) in *manicômios* [EN: mental asylums] where they were subject to gross violations of their human rights, including neglect, abuse and social isolation.

In 2001, a major reform of psychiatric care was approved in the Brazilian Congress (Law 10.216), which built on the recognition of mental health in the 1988 Constitution and led to a reconceptualization and creation of the idea of the 'citizen burdened by mental suffering' (Biehl, 2005, p.133). Furthermore, the creation of the SUS sought to move away from the hospital-centric healthcare model and increase healthcare coverage to the whole population through Family Healthcare initiatives (Tomasiello, Bazzo, Parga, Servo, & Pereira, 2021). In terms of success, the SUS and its high population coverage make it one of the most celebrated health systems in the world.

However, despite the significant reforms in the health and psychiatric systems, they have not yet resolved the country's health inequities, despite considerable advancement in healthcare access as a result of universal coverage provided by the SUS, as challenges persist in the comprehensive implementation of policies. Despite the major health reforms and the creation of the SUS, post-constitution state support did not substantially increase

for people with disabilities (Block & Cavalcante, 2014), who remained at a significant disadvantage generally, but also specifically in relation to access to healthcare.

Mobilization of the disability rights movement and attention to the lack of access to healthcare for this population led to the creation of the *Política Nacional de Saúde da Pessoa com Deficiência* in 2002 [EN: National Health Policy for Persons with Disabilities (PNSPCD)], which is praised for its progressive and social model based approach to removing barriers to access (Lyra et al., 2022). Yet implementation of the PNSPCD has faced multiple obstacles influenced by social, political and economic factors, including neoliberal attacks on social policy and chronic underfunding of the SUS (da Cunha et al., 2022; Lyra et al., 2022; Massuda, Hone, Leles, De Castro, & Atun, 2018). These issues have contributed to the persisting inequalities experienced by people with disabilities in relation to healthcare access today in Brazil.

A key criticism of the health and social assistance reforms is the over-medicalisation of health issues, disability, poverty, and mental health. Maluf (2015) notes that public services meant to replace the *manicômios* through psychosocial networks, such as Psychosocial Care Centres (CAPS) and basic health care services, still reproduce the same logic: institutionalising, medicalising, and sometimes asylum-like practices, focusing on physical and medical concepts of psychological suffering. Despite the social model of disability in Brazilian law, inconsistent diagnostic processes allow medical approaches to dominate health services (Ferst & Nogueria, 2025).

The medical model also prevails in the Unified Social Assistance System (SUAS), which administers social protection programmes. Critics argue that SUAS pathologises people with disabilities and those facing social inequality (Panisson, Gesser, & de Andrade Gomes, 2018). More holistic approaches did make their way into the modern reforms, however. Some spiritist therapies have been integrated into psychiatric treatments in Brazil (G. Lucchetti et al., 2012), although there is limited understanding and scientific evidence of their effectiveness (A. L. G. Lucchetti, Peres, Vallada, & Lucchetti, 2015; G. Lucchetti et al., 2012). Likewise, it has been suggested that despite there being little knowledge of disability studies and theories, many psychiatrists take an approach more aligned with the social model of disability (Rios & Andrada, 2015). However, while significant strides were made, over-medicalisation and underinvestment remain as key barriers to Brazil's health and psychiatric reforms.

3.2.6. Impacts of disability activism in 21st-century Brazil

A series of significant advancements in both the mobilisation of disability activists and the formalisation of the rights of people with disabilities have marked disability activism in the

first quarter of the 21st century. The CRPD, which Brazil signed and ratified in 2007, moved disability dialogue away from charity and medical approaches pushed by the earlier philanthropic movements towards rights-based approaches rooted in the social model, including enshrining these in laws and policies (Kirakosyan, 2016). This also bolstered efforts within the disability rights movement, including a move towards celebrating disability and neurodivergent identities. For example, the first *Orgulho Autista* [En: Autistic Pride] demonstrations and events in 2008 and the first *Orgulho Louco* [En: Mad Pride] parade held in 2007, drawing inspiration from the LGBT pride marches that had begun a decade earlier to de-stigmatise marginalised identities and garner public support for rights claims. This signifies a move of mainstream movements towards an approach that aligned with other international disability rights movements, which pushed a positive identity-based model to push back against charity and medicalised approaches that stigmatised disability.

This period was also significant for further developing the Brazilian legal understanding of disability and the influence of parent-led disability activism. The early 2000s saw what Block and Cavalcante describe as a 'new wave of parent-led movements' formed to provide solutions to the problems of the lack of education and treatment for autistic children and adults.' (2014, p. 89). Part of this wave of activism was driven by a push towards the recategorization of Autism as a disability, rather than a mental health condition. Since psychiatric definitions since the Psychiatric reform saw people with mental health conditions as 'people with severe mental suffering', autistic people were also seen within this bracket, questioning whether Autism was a disability, that could claim a positive disability identity and rights as people with other impairment types have been able to do, or whether they were a group of people in need of medical treatment to cure their 'suffering'. Rios and Andrada (2015) suggest that parents during this period occupied a space that was neither searching for a cure for autism nor outright rejection of treatment. Instead, they took on an identity approach to disability in order to negotiate access to both treatment and the right to social inclusion. Lobbying by parent associations was successful, and by 2012, Congress passed the proposed legislation. The president signed the new law (12.764) and altered an existing disability rights law (8.112) to provide Autistic citizens the same rights as other citizens with disabilities.

After a decade of discussion in Congress and pressure from disability movements, the bill on the Statute of the Person with Disabilities, or the *Lei Brasileira da Inclusão (LBI)* [EN: Brazilian Law of Inclusion] (BRASIL, 2015), passed its lower house. The bill provides comprehensive protections, including access to education, healthcare, transportation, and employment, mandating reasonable accommodations and accessibility in public spaces, bringing the law closer in line with the CRPD. However, some provisions of the bill do not fully agree with the Convention, for instance, the definition of disability, which disability activists argued was still based on the medical model (ABRAÇA, et al. 2015). Although there

has been an effort in recent years to make their content more consistent with CRPD through various revisions, the hard-won progress has also faced the threat of being rolled back.

Brazil's Law of Education for People with Disabilities, passed in 2008 and part of the broader National Education Guidelines and Framework Law, ensures inclusive education for students with disabilities at all educational levels. However, Brazil retained a dual education system– through specialised, segregated settings such as the *clínicas-escolas* [EN: clinic-schools] run by APAE and through inclusion in mainstream school settings. In 2020, inclusive education practices were threatened when the far-right President Jair Bolsonaro signed Decree Nº 10.502, proposing new legislation that encouraged segregation of children with disabilities and a rollback on inclusive education (Cafardo, 2020). The following year, the Minister for Health publicly declared that 12% of children with disabilities have a degree of disability which means they are impossible to live with and that they disturb the learning of other students in the classroom (Alves, 2021), in defence of the Decree and reforms to promote segregated education. The decree was eventually suspended following controversy and pushback from the disability rights movement, but other laws proposed during this time are still being discussed in Congress, amid ongoing backlash from disability rights organisations.

3.2.7. The impacts of 21st Century health emergencies on activism

Brazil was significantly impacted by two major health emergencies in the early 21st century that had significance for social justice movements. As touched on in the introduction to this thesis, in 2015, Brazil became the epicentre of a Zika epidemic, which caused Congenital Zika Syndrome (CZS) in babies born to infected mothers. CZS is the term used to describe a series of diagnoses, including various health issues and lifelong disabilities that affect children's development along normative trajectories. Most cases were confirmed in the Northeast region (Secretaria de Vigilância em Saúde & Ministério da Saúde, 2018) and disproportionately in peripheral areas with poor access to sanitation (Souza et al., 2018). Despite poor sanitation being one of the main causes of the epidemic, the government response was 'biomedical and reactionary' (Matta, Nogueira, & Nascimento, 2019), largely responsibilised women for individual action to eliminate the mosquito and not get pregnant (Antunes, Oliveira, & Rebouças, 2018; Matta et al., 2019; Porto & Costa, 2017). This approach distracted from the responsibility of the government to provide for its citizens with disabilities, including the ones most recently born with CZS.

Mothers, the majority of whom were single, young and self-identified as Black or *parda* (Human Rights Watch, 2017), were left struggling to get adequate access to health and therapeutic services and social assistance to meet their children's development needs (Bachtold, 2019; Venancio de Siqueira, Lobato, Vaitsman, Hollanda, & Nóbrega, 2019). Many gave up work to care for their children full-time, leaving them financially reliant on the state

or their partners (Scott et al., 2017). In response, mothers started forming Zika associations across the country. For the most part, these associations provide peer support, but some groups have engaged in more political activities, organising themselves on behalf of their children's rights to inclusion in society via access to public healthcare and transport, education and citizenship rights (União das Mães de Anjos, 2019; Damasio, 2016) (União de Mães de Anjos, 2019) but also the rights of the families to receive support as carers (Soares, 2018) and compensation for the failings of the government.

Four years later, Brazil was severely affected by the COVID-19 pandemic, becoming one of the hardest-hit countries. By September 2020, Brazil had the third-highest number of cases and deaths, with the highest rates per million people—20,598 cases and 626 deaths, respectively (Worldometer, 2020). It was been argued that the neglect of Jair Bolsonaro's government to react to the Covid-19 crisis amounted to genocide owing to the disproportionate impact on the Black, Indigenous, elderly and vulnerable populations (Brum, 2020) with Afro-Brazilians experiencing risk of mortality 1.5 times higher than the White population (Martins-Filho et al., 2021). The pandemic has hindered the capacity of many social movements to organise activities, but has also led to new movements, new collaborations and increased reliance on the internet. WhatsApp, Facebook and Instagram became essential for communication between members and movements. Both health emergencies revealed that socioeconomic factors, which influenced who was most affected, were largely overlooked in the state response, disproportionately impacting the Black population, the socioeconomically marginalised, women and people with disabilities. This led to a wave of activism from both the disability rights and women's rights movements.

3.2.8. Brazilian disability studies

Brazilian Disability Studies, despite still being a relatively young and unknown field, has also developed during the 21st century. Mello et al. (2016) note that international Disability Studies scholarship influenced Brazil, and the first 'social model' influenced work was produced, mainly by non-disabled scholars who did not identify with the movement in the fields of Psychology and Education. However, during the second decade of the 2000s, there were several Disability Studies conferences held across the country. The concepts have continued to develop, under significant influence from feminist theory, to reject defining disability solely in terms of societal barriers and instead take an approach that appreciates the interaction of impairment with societal barriers (Guedes de Mello & Goyena, 2020). As a result, Brazilian disability studies offer essential contributions in the understanding of disability that go further than the distinction of impairment and disability to include inequality and social, cultural and political factors, including recognising the experiences of discrimination by association of women caregivers (ibid). Therefore, according to Silva and Oliver,

> *'disability cannot be understood only by the presence of bodily impairments and / or injuries; however, this should also be seen as a result of the ways of life marked by inequality and social exclusion and consider economic, political and cultural aspects, in addition to issues of physical accessibility and communication as determinants of disability.'* (2019, p. 286)

However, Mello et al. also highlight that whilst Brazilian Disability Studies has been influenced by feminist theory to pay significant attention to issues of gender, the field has been slow to take up issues of race, ethnicity and class in the same way (Mello et al., 2016). Interestingly, this oversight is reflected in the documentation of the disability rights movement, where often Black activists' contributions to activism and public policies are omitted. This omission is seen in the lack of representation of Black activists, like Marco Antonio Pellegrini, in key spaces such as the Museum of Inclusion in São Paulo, constituting an essential piece of evidence (Viegas & Avery, 2025). I draw a comparison here between such erasure from history and the debilitation of these populations through neglect or direct actions of the state and other actors.

Within the Brazilian parent activism literature, the lack of attention to racial dynamics or even an acknowledgement of the exclusion of the Black and indigenous population from mainstream parent organising is sorely lacking. As noted earlier, the literature mainly focuses on mainstream parent organising dominated by the elites and middle classes, who are much more likely to be white, owing to the socioeconomic disparities along lines of race. I reiterate here that the research indicates the approaches of these families draw on their social capital as members of privileged classes (Bregain, 2013; Nunes, 2014; Rios & Andrada, 2015). However, if the social capital of parents of children with disabilities informs approaches to activism as suggested by the Brazilian studies, then it follows that mothers with different social capital may take different approaches or experience barriers to enacting activism as understood in the existing literature. This further suggests that activism approaches may differ owing to multiple intersecting oppressions experienced by families in peripheral contexts unreached by mainstream organising, and that the existing literature and theoretical framings are insufficient to explain this.

It is only within the Zika literature that there begins to be more acknowledgement, albeit still little analysis, of race and gender regarding the impacts of Zika and the related activism of mothers of children with Congenital Zika Syndrome (CZS). The predominantly Black mothers' organising has and can be analysed in terms of Black feminist organising in recognition of the historic, cultural and political background and the impacts on both their context and political articulation (Valentes et al, 2024). Yet, most of the Zika literature merely mentions this in passing without analysing how racial discrimination can be a factor in the production of disability and access to services, the subsequent experiences of mothers and children, and how these factors have shaped their actions and activism. As a result of this oversight, little is known about the relationships between mainstream

organising and parent activism in more informal contexts, due to a lack of access to or trust in formal structures of power along lines of social class and race.

3.3. Persisting inequalities & the current landscape

Present-day Brazil is characterised by persisting inequalities that play out along lines of race/colour, gender, disability, sexuality, socioeconomic status, and geographic location linked to multiple and intersecting systems of oppression. For people with disabilities in peripheral communities, often their lives and those of their family members are experienced at the intersection of multiple systems, including but not limited to ableism, racism, and sexism. Whilst explicit research on the experiences of Black people with disabilities and their families is sorely lacking, which is pointed out to be an important piece of evidence of this population's historic marginalisation (Viegas & Avery, 2025), there is enough adjacent data to provide an overall picture of the context surrounding these families. I present here some of the key relevant persisting inequalities impacting people with disabilities, their families and communities in peripheral areas in Brazil.

3.3.1. Modern slavery

Brazil's key historical role in the trans-Atlantic slave trade continues to impact today's modern labour market and high rates of modern slavery practices (Bansal et al., 2023). Modern slavery in Brazil is therefore within the top ten highest global rates, with over a million people or 5 in every 1000 of the population, estimated to have experienced forced labour or marriage in 2021 (Walk Free, 2023). I include this here as there are parallels between domestic work, which is largely undertaken by Black women, and domestic labour practices and lack of legal protections of workers lead to high rates of work undertaken in slave-like conditions. Although not widely acknowledged, slavery continues to be deeply connected to disability in Brazil, as people with disabilities, and particularly those who are in situations of social vulnerability, also linked to socioeconomic status, race and gender, are made vulnerable to exploitation.

There have been regular cases of Black people found in slave-like conditions working in the households of elite, white families in Brazil's recent history. One of the most recent. Sônia Maria de Jesus, a fifty-one-year-old Black, Deaf woman who was found in southern Brazil in June 2023, having worked in slave-like conditions at the house of a judge for over forty years, without having the opportunity to learn sign language or go to school, or even leave the house (V. Oliveira, 2025). Despite evidence of serious violations of her human rights, including not being registered with the social security system until age forty-five, Sônia was returned to the house of the family where she had been enslaved, where a legal battle

ensues, complicated by an application for socio-affective paternity by the judge (ibid). The case has been said to set a dangerous precedent for future victims of slavery by a judicial system that is allowing and institutionalising a culture of slavery (León, 2024). I argue that this case demonstrates the intersection between disability, race and gender discrimination in the context of modern slavery and domestic work that is connected to Brazil's historic entanglement with the transatlantic slave trade and therefore relevant to the study of disability as an analytical category through an intersectional lens.

3.3.2. Health inequity and environmental racism

Despite the lack of explicit research on the topic, geographic location can tell us a lot about the everyday experiences of people with disabilities living in peripheral communities, including how they are impacted by environmental racism, or the disproportionate exposure to environmental hazards in comparison to those living in urban core locations. Data from the 2022 census showed that Black and indigenous people in Brazil were more likely to live in areas that experience disproportionate negative impacts of climate change events such as flooding and landslides (IBGE, 2022). These events already pose higher rates of risk for people with disabilities, who are more vulnerable during natural disasters, health emergencies and humanitarian crises (UNDDR, 2023). Other studies using census data indicate that the Black population are much more likely to reside in areas lacking wheelchair accessibility, as well as adequate walkways, sanitation, lighting, and drainage (Boing, Boing, & Subramanian, 2021) indicating that this population is more likely to experience issues of mobility that impact public participation and health equity. In addition, peripheral populations are disproportionately exposed to public health risks through poor urban planning in the areas where they live. Only half of Black residents in the Northern region have access to sanitation (IBGE, 2022), indicating a significant public health risk.

Health and socioeconomic disparity can also be linked to disability and race and violence. First of all, the Black population in Brazil experience a general lack of access to healthcare related to their lower socioeconomic position in relation to the white population (N. N. da Silva et al., 2020). However, disparities are also regional; notably, the regions with the most significant healthcare access disparities are the north and northeast, which are not only the poorest but also home to the largest Black populations (Coube, Nikoloski, Mrejen, & Mossialos, 2023). In parallel, the northeast has the country's highest reported rates of disability, at around 5.8 million people or 10.3% of the total population of people with disabilities, as well as being the region with the highest rates of illiteracy and unemployment and wage inequality between those with and without disabilities and the lowest rates of education and pay (IBGE, 2023). Disproportionate impacts of violence, including high rates of police violence directed towards Black and peripheral communities are also relevant. Whilst disaggregated statistical data is not publicly available, non disaggregated data and

anecdotal evidence points to particular risk, especially for young, Black men and boys with invisible disabilities (Minority Rights Group, 2022).

The north and northeast regions also experience the highest rates of violence, and Black people with disabilities and women in particular are especially vulnerable to institutional violence, domestic violence, extrafamilial violence, and homicides all over the country (IPEA, 2024). Despite a lack of data, anecdotal evidence also points to increased vulnerability of this population to police violence (Minority Rights Group, Vidas Negras com Deficiência Importam (VNDI), & University of York, 2022). There is likely to be significant underreporting of disability rates within peripheral areas because of the issues in accessing healthcare services, and therefore diagnosis, as well as high rates of stigma and lack of awareness of disability benefits that can be accessed when disability is diagnosed.
Yet policymakers and scholars often overlook the links between poverty, violence, racial discrimination, disability, gender and care.

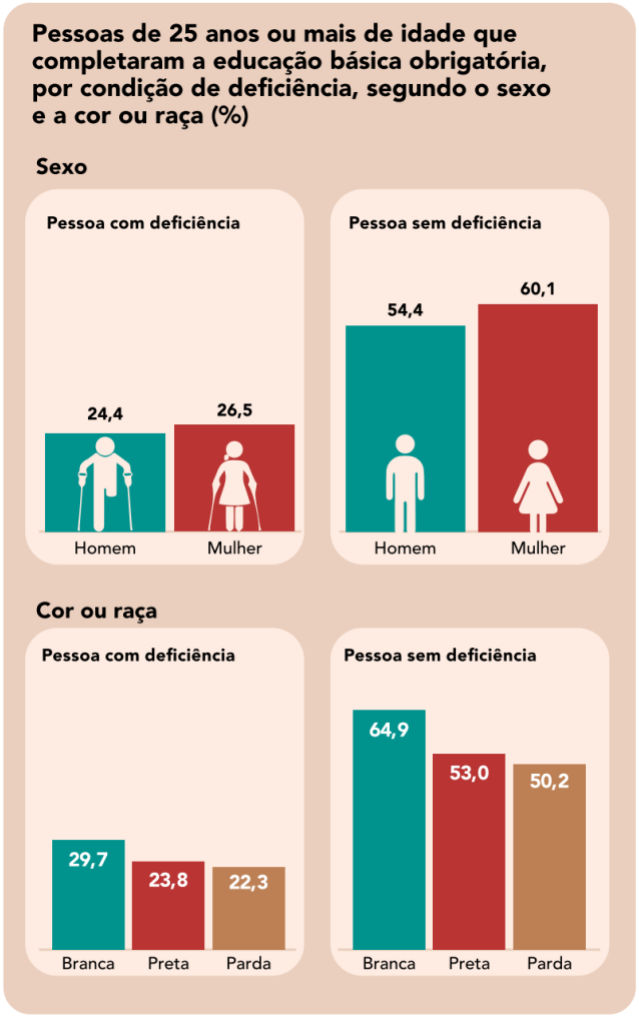
Owing to the healthcare inequity the Black population faces, it is more than likely that the higher rates of disability indicated are a direct result of poor access to healthcare. Furthermore, people with existing disabilities residing in peripheral areas are more likely to face barriers to healthcare access that are lifesaving or prevent worsening or developing new impairments. For example, Black populations face limited access to high-complexity healthcare services *(PT: serviços de saúde de alta complexidade)*, primarily because these services are concentrated in urban centres, which are predominantly inhabited by the white population, with a lack of access compounded by poor transport links between peripheral areas and urban zones (Tomasiello et al., 2021). Looking at this type of service is particularly relevant when thinking about social inequity relating to disability through the lens of Kafers' (2013) political/relational model as these include access to higher cost services such as cancer treatments, physiotherapy and spinal surgeries – medical services for conditions that might be discounted under more narrow definitions of disability.

Adding other intersecting factors builds a picture of the complexity of intersectional discrimination in Brazil and how it plays out in terms of health and wellbeing along lines of race/colour, gender, disability and sexuality. For example, access to healthcare for Black women is complicated by structural racism and sexism. A study evaluating access to preventative health services showed that 7.9% of Black women reported "good" access in comparison to 15.4% of their white counterparts (Goes & Nascimento, 2013). Health data backs up this anecdotal evidence. For example, a national-level study on maternal health showed that from 2015 to 2022, the risk of maternal death for Black women in Brazil was twice that of white women (Maria do Carmo Leal, Granado, Bittencourt, Esteves, & Caetano, 2023). Similarly, Black and *parda* women are more likely to die from breast and cervical cancers than white women, with disparities widening in some regions (J. L. da Silva, de Albuquerque, Rodrigues, Thuler, & de Melo, 2024; Guimarães Ribeiro et al., 2024; Marcelino

et al., 2021). This is an important consideration for this study as we consider the health and well-being of women carers, the barriers they already face, and the obstacles facing their children. Considering people's experiences from an individual perspective and within the family context can therefore allow a holistic approach to analysis without pitting the needs and rights of family members against each other.

According to a study based on the 2010 demographic census in Brazil, the prevalence of visual, hearing and motor disabilities is almost always the highest in indigenous populations (Dias Junior & Verona, 2018). International studies indicate that higher rates of disability and mental health issues within Indigenous communities are linked to violation of Indigenous peoples' rights; higher risk of violence, lack of access to healthcare and sanitation, impacts of resource extraction projects and environmental degradation (United Nations, 2013;2024). Yet, Indigenous people with disabilities continue to be systematically erased in official publications by the Brazilian government, including from published research about people with disabilities. Indeed, disaggregated disability data showing the race/colour self-identity category was only published for the first time in 2023. Still, it did not include the 'indigenous' or 'yellow' (Asian) category in official publications or provide data on children (IBGE, 2023) - see figure 3.1. This lack of publicly available, disaggregated data contributes to the absence of specific policies tailored to the needs of Black and Indigenous children with disabilities, who are often overlooked by general policies aimed at children, children with disabilities, or Black and Indigenous adult populations. Indigenous disability activists report that data on Indigenous children with disabilities is especially limited and underreported, making it harder for them to access basic services and hindering the development of targeted policies and programs (Minority Rights Group et al., 2024).

Research shows that Black and Indigenous children face elevated infant mortality rates and a greater risk of preventable deaths from causes such as malnutrition, diarrhoea, influenza, and pneumonia (Rebouças et al., 2022). In the North and Northeast, the regions with the largest Black populations, the poorest children have the least access to healthcare services compared to the other areas and age groups (Coube et al., 2023). As demonstrated earlier, access to healthcare services within peripheral areas is precarious, meaning that children with disabilities relying on such services living in peripheral areas are likely to be amongst those most impacted, especially those relying on high complexity health services. Furthermore, lack of access to education, including denial of access to school places, inadequate classroom support (Minority Rights Group et al., 2024) and stigma on grounds of race and disability impacting children's self-esteem and learning capacity (Scholz & Freitas, 2021), further indicating how children with disabilities in peripheral areas are subject to multiple and intersecting systems of oppression.



Fonte: IBGE, Diretoria de Pesquisas, Coordenação de Pesquisas por Amostra de Domicílios, Pesquisa Nacional por Amostra de Domicílios Contínua 2022.

Figure 3.1: Graphic from the Pesquisa Nacional por Amostra de Domicílios Contínua: Pessoas com deficiência 2022 [EN: Continuous National Household Sample Survey: People with Disabilities 2022] by IBGE, 2023. The graphic shows disaggregation by disability, gender, and race/colour, but only in the white, black, and parda categories.

3.3.3. Disability diagnosis and classification

Access to disability services, including day centres and rehabilitation services, benefits, such as the BPC, and affirmative programs, such as education and employment quotas for people with disabilities in Brazil, often depends on a disability evaluation that decides an individual's eligibility. For access to some services and benefits, for example the BPC, it is necessary first to obtain a medical report for people with disabilities [*PT: Laudo Médico para pessoa com deficiência (PCD)*] from a medical professional specialised in the relevant area of disability from either a public or private healthcare provider, including the disability

classification against the International Classification of Diseases (ICD) and follow the standard classification set out in Brazilian Law Decree No. 3,298/99 (Brazil, 1999). The necessity of first obtaining a medical diagnosis within a medical setting presents an additional barrier for people with disabilities, who already face significant obstacles in accessing the SUS (Cunha, 2022). For people with disabilities in peripheral communities, these barriers are likely to be significantly greater. Therefore, the likelihood of being able to access a medical report is considerably more complicated.

Brazil's fragmented disability evaluation system also lacks standardisation and predominantly uses a binary, biomedical model. In their review of legal definitions of disability in Brazil, Ferst & Nogeuria (2025) point out that the lack of clarity and domination of medical model interpretations of disability impede access to rights and benefits that exacerbate social exclusion of people with disabilities. Most disability evaluations—whether for medical diagnosis or access to social assistance—are based on the International Classification of Diseases (ICD-11), which has a biomedical grounding (Ministerio da Mulher da Família e dos Direitos Humanos; Secretaria Nacional dos Direitos das Pessoas com Deficiência, 2021). Firm reliance on the ICD-11 to validate disability identification, therefore, reinforces the dominance of a biomedical approach to disability across sectors providing services and support.

However, despite the dominance of ICD-11 reliance, there is no single, unified system for evaluating disability in Brazil. Instead, each organisation or program determining eligibility for disability-related policies uses its own evaluation process, with differing methods, criteria, and parameters. A report by the Ministry of Women, the Family and Human Rights (2021) noted that out of 34 policies for people with disabilities, 30 have distinct evaluation methods based on a binary approach. This means categorising individuals as either disabled or not without adequately assessing the social and environmental factors of disability. This approach often excludes the most vulnerable and emphasises an individual, medicalised conceptualisation of disability, rather than a more holistic approach. In addition, assessments differ across organisations, requiring individuals to undergo multiple evaluations, provide varying documentation, and meet inconsistent criteria. As a result, someone considered to have a disability under one system may not meet the requirements under another.

Some evaluations may also incorporate the International Classification of Functioning, Disability and Health (ICF), although this is less common and follows a binary, biomedical approach. Public healthcare centres often specialise in specific disability classifications under the ICD, meaning individuals may need to research and travel long distances to access a qualified healthcare professional to evaluate and provide a medical report for their disability type, which aligns with regulations. Overall, Brazil's reliance on biomedical evaluations is not aligned with both the Brazilian Inclusion Law (Lei Brasileira de Inclusão - LBI) (2015) and the Convention on the Rights of Persons with Disabilities (CRPD) (2006),

which advocate for a biopsychosocial model. At the time of writing, Brazil was engaged in discussions around the creation of a National Unified Disability Assessment System (SISNADEF), intended to standardise evaluations and align them with national and international legal frameworks. However, this system has not yet been finalised or implemented.

3.3.4. Social protection and support for children with disabilities and their families

Brazil has several social assistance policies designed to support children with disabilities and their families, in addition to the statutory laws already discussed, which will be briefly analysed here. The Ministry of Development and Social Assistance, Family and Fight Against Hunger has responsibility for the National Social Assistance Policy, which is administered via the Unified Social Assistance System (SUAS) 'through services, benefits, programs and projects' (Ministério do Desenvolvimento e Assistência Social, 2025, n.p). The Benefício de Prestação Continuada (BPC) [EN: Continuous Cash Benefit] provides financial assistance to low-income individuals with disabilities who are unable to support themselves. The Lei de Cotas para Pessoas com Deficiência (PCD) [EN: Quota Law for Persons with Disabilities (PWD)] (1991) mandates that companies with more than 100 employees must hire a percentage of people with disabilities, promoting their economic inclusion. These policies aim to reduce inequality and enhance the well-being of people with disabilities. Additionally, laws provide tax benefits, such as exemptions for parents of children with disabilities, and allow for paid leave from work under the Social Security Law to care for a child with a disability.

There are also non-disability-focused child benefits relevant to children in the peripheries. For example, Salário Família [EN: Family Benefit] is a family allowance paid to employees, including domestic workers and casual workers, according to the number of dependent children they have, which is also conditional on income and other factors (Ministério da Previdência Social, 2020). In addition, Bolsa Família [EN: Family Allowance]is a conditional cash transfer programme provided to the poorest families, if they adhere to criteria such as vaccination and school attendance. Families with a member with a disability are also prioritised under Brazil's flagship social housing programme for low-income families, Minha Casa Minha Vida [EN: My house, My Life] (Ministério das Cidades, 2022).

However, despite social protection schemes in Brazil receiving global acclaim, their efficacy has been questioned. Kidd and Huda (2012) note that *Bolsa Familia* has a limited impact on poverty reduction in comparison to other social protection schemes, is not guaranteed to families, since each municipality has a fixed quota, and is not enough to lift families out of

poverty on its own. Silva et al. (2017) further identify a range of other barriers to access, including conditionality on school attendance; cutting of *Bolsa Familia* due to receipt of the BPC; family income threshold to be classified as 'extreme poverty' to be eligible for the BPC; and lack of documentation in order to access benefits. As a result, there are issues with social security coverage for many families, with the majority of those uncovered belonging to Brazil's lower-middle income category (Soares & Souza, 2012).

Lack of social protection coverage also impacts children with disabilities. For example, as of 2015, more than 70% of children with disabilities were not receiving the BPC because of the low-income threshold to attain it (Wapling, Schjoedt, & Kidd, 2020). These restrictions and barriers add to the financial insecurity experienced by families of children with disabilities. The BPC's eligibility criteria, which tie the eligibility to the total family income, are additionally disempowering to people with disabilities as it forces two scenarios: the benefit being received on condition of an extremely low total family wage, or financial reliance on the family.

3.3.5. Institutionalisation

The ongoing institutionalisation of people with disabilities and further divisions along disability type, social class and race are indicators of the persisting inequalities within Brazilian society and are directly linked to the lack of support. There are no accurate statistics published on the number of people with disabilities institutionalised in Brazil, and no disaggregated data that would shed light on other identity characteristics of those institutionalised. Information provided to the UN Committee on the Rights of the Child (CRC) was also obscure; stating 3,813 children with disabilities and 4,421 children with mental health disorders living in alternative care institutions and 1,126 children living in an institution *'exclusively for children and adolescents with disabilities'* (UNCRC, 2025, p. 21), yet not providing overall numbers nor making clear whether these numbers were duplicated. However, the inconsistency in the reporting and lack of disaggregated data on race/colour and gender make further analysis difficult.

The same report provided data on the number of children with disabilities living with their families. Although certainly an underestimate, national figures are at 99%, with many states stating figures at 100%. Only twelve regions showed a percentage of children not living with their families, between 1% and 5%. Of these states, three were in the North; four in the northeast; two in the central west; two in the southeast, and one in the south. Two of these states, Mato Grosso do Sul and Roraima, which also had the highest rates of children with disabilities not living with their families, 2% and 4%, respectively, are amongst the states with the highest Indigenous populations. The state with the highest number of children not living with their families (5%) is in the North (Rondônia). The distribution of these figures

suggests children separated from their families are more commonly found in the poorest regions and the regions with higher Indigenous and Black populations, suggesting a causal relationship between poverty, racial discrimination and institutionalisation.

There has been very little research done on the persistence of institutionalisation of people with disabilities following the psychiatric reform, and even less to investigate the other social characteristics of those institutionalised. An investigation by Human Rights Watch (2018) between 2016 and 2018 into nineteen institutions for people with disabilities across four states estimated that there are more than 10,000 people with disabilities living permanently in institutions, and around two and a half thousand institutions that housed children with disabilities, although this is likely to be an underestimate. The Human Rights Watch report (2018), soberly named 'They Stay Until They Die', showed that violations of rights regularly occurred, including restraining, guardianship (deprivation of legal capacity), medication without consent, and education deprivation (ibid). This is consistent with other research on institutionalisation worldwide (de Bruin-Wezeman, 2020). Yet, despite the worldwide progress towards community-based solutions in line with the CRPD, it remains a persisting issue.

National data regarding the race and age of individuals with disabilities living in institutions is not currently available to the public, nor was race included as an analytical category by the Human Rights Watch research team. However, research and anecdotal evidence suggest that Black children with disabilities are disproportionately placed in state care, resulting in their overrepresentation in institutional settings (Minority Rights Group, Vidas Negras com Deficiência Importam (VNDI), & University of York, 2022). For instance, a 2011 study conducted in Rio de Janeiro revealed that 66.9% of 112 children residing in segregated institutions for children with disabilities were Black, while 29.5% were white (Rizzini & Almeida, 2011). In comparison, among 61 children with disabilities living in mixed (non-segregated) institutions, 67.3% were Black and 29.5% were white (ibid). This stands in contrast to the overall population of Rio de Janeiro, where 51.7% identify as Black and 47.4% as white (IBGE, 2010). Since institutionalisation of people with disabilities is often related to the socioeconomic positions of families, it is proposed that Black and Indigenous families, who are more likely to live in socioeconomic precarity in Brazil, are more likely to have their children with disabilities institutionalised.

3.3.6. Care work

Continuing the legacies of Black women's roles in the slavery system, Black women continue to make up most of the domestic and care labour force in Brazil, providing support for white, middle-class families in informal employment, for less than minimum wage and with precarious social security. Afrobrazilian feminist Lélia Gonzalez wrote in 1979 how Black

women are stereotyped and relegated into two roles: as "domestics" or as "mulatas" - a term often used to refer to women who are sexualized as part of a national exoticised image, which perpetuates a cycle of marginalization for Black women through labour, while reinforcing the myth of racial harmony in Brazil. Gonzalez's analysis of Black women as domestic workers still rings true in present-day Brazil, as demonstrated by statistics from the 2023 National Household Sample Survey [PT: *Pesquisa Nacional por Amostra por Domicílio (Pnad)]*. The survey showed that women made up 91.1% of all domestic workers, 66% were Black women, and the average salary was less than half of that of women engaged in other types of work (DIEESE, 2024). Moreover, 16% of Black women had domestic services as their primary source of income, compared to only 9% in the case of non-Black women; Black domestic workers were twice as likely to experience poverty or extreme poverty and earned 87% the income of non-Black workers, despite both being below minimum wage (ibid).

Despite assumptions that people with disabilities are only on the receiving end of care, the rates of women with disabilities in domestic work in 2022, including care work, were 18.8%, significantly more than women without disabilities, who made up 12.2% (IBGE, 2023). The higher rates of women with disabilities engaged in domestic work is further explained by statistics showing that Black women are more likely to be disabled than any other group in Brazil; the 2010 census showed that almost a third of Black women have disabilities (IBGE, 2010) and that this group are the most likely to be engaged in precarious, informal work (IBGE, 2022). This indicates that many of the women providing care are likely also to have disabilities themselves, which questions the assumption of a disabled/non-disabled binary in the carer/cared-for dichotomy that is so often present in academic and policy discussions.

Although it falls under the umbrella of domestic work, these statistics likely do not account for familial unpaid care work undertaken by women for family members with disabilities, and official statistics for the whole country do not exist. Furthermore, separating what care work tasks go beyond the typical parenting role, especially for younger children, can be complicated. However, results from ELSI-Brazil (Brazilian Longitudinal Study of Aging) using a representative sample of the population over 50 indicate that care continues to be primarily a responsibility of the family at 94.1% and women, at 72.1%, with 25.8% of all caregivers having to stop work or study to take on a care role, and only 9.2% receiving payment (Giacomin, Duarte, Camarano, Nunes, & Fernandes, 2018). Since this and many datasets do not disaggregate data by race, it is difficult to get a picture of the racial dynamics of unpaid family care work for people with disabilities. However, by looking at the socioeconomic disparities based on race and geographic location within the country, as presented earlier, we can surmise that families in peripheral areas, who are more likely to be Black, are less likely to be able to afford outsource care from professionals. Therefore, Black women and girls are more likely to provide unpaid care work in the home. This work, including its gender

and racial disparities, is consequently rendered invisible through the lack of data collection and general attention paid to the issue by the Brazilian government historically.

At the time of writing, there is no care policy that offers financial support to people with disabilities who depend on care or assistance. Consequently, many continue to rely on unpaid family care, a practice rooted in the long-standing, yet persistent, belief that caregiving is a responsibility primarily for women and girls, while disability is often viewed as a private family issue (Patrícia Maccarini Moraes, 2019). This perspective reduces people with disabilities to mere recipients of charity, rather than acknowledging them as rights holders to whom the state has an obligation (McLaughlin, Goodley, Clavering, & Fisher, 2008). It also limits the autonomy of individuals and their families in deciding who should provide their care and support. Additionally, factors such as race/ethnicity, socioeconomic status, poverty, disability, and gender play a crucial role in shaping who can afford to pay for private care and which families are most vulnerable, as current policies and support systems fail to reach them.

As a result of ongoing advocacy from the disability movement and the women's movement, There are continuing discussions about the introduction of a National Care Policy [*PT: Política Nacional de Cuidados (PNaC)*], with the objective, amongst others, of 'guaranteeing the right to care, in a gradual and progressive manner, from the integral and integrated perspective of public policies that recognize the interdependence of the relationship between those who care and those who are cared for' (Ministério da Mulher, 2023, p. 66). The policy proposal is currently under a period of public consultation, through which there has been considerable engagement of the most marginalised sections of Brazilian society (Ministério da Mulher & Ministério do Desenvolvimento e Assistência Social, 2023). Consequently, there has been public recognition by the Ministry of Development and Social Assistance of the specific issues facing Black, indigenous and quilombola populations, single mothers, of poor and peripheral populations and the need to consider these inequalities in the formulation of a care policy that is antiracist, anti-ableist, non-discriminatory on grounds of gender, and anti-ageist amongst other progressive principles (Ministério do Desenvolvimento e Assistência Social, 2023). This marks a step forward in progressive and intersectional thinking around issues of care, race and disability. However, there are many hurdles before the proposal is solidified into its final form and passed through Congress, not to mention financed and implemented.

3.4. Chapter summary

This chapter provides an intersectional analysis of disability, familism, and activism throughout Brazil's history, starting with the colonial period and continuing until the mid-21st century, and ending with a present-day analysis. The chapter aims to follow the CDS

framework laid out in the previous chapter that contextualises disability geographically, culturally and historically. This chapter contributes to a gap in the Brazilian disability studies literature that fails to analyse current conceptualisations of disability and care within the historical context of slavery and the persisting inequalities that have shaped the sociopolitical landscape of the country. This chapter lays the groundwork for the analysis in the empirical chapters and the methodology laid out in the following chapters. Expanding on Lilia Ferreira's (2008) work, I aimed to demonstrate that disability is central rather than supplementary to understanding Brazil's history, despite remaining overlooked in historical and present-day analysis. The chapter also presented an analysis of how the legacy of slavery is linked to the current situation of Black women's domestic labour in the country, including unpaid familial care work for family members with disabilities.

Furthermore, the chapter presents an overview of how disability activism has evolved alongside changing conceptualisations of disability since the era of the Brazilian Republic, linked to the Hygienist movement and the growing dominance of medical science. Whilst early disability activism tended to take a philanthropic or charity model approach to improving the lives of people with disabilities, the presence of organisations of people with disabilities (OPDs) from the middle of the 19th century was catalysed during the democratisation process post-military regime. The role of OPDs formed the basis of the modern disability rights movement, which flourished at the end of the 19th century and was further boosted by international disability rights initiatives. The chapter finishes with an overview of the persisting inequalities present in Brazilian society that influence the experiences of children with disabilities and their families in the peripheries. Despite a progressive legislative system and public policies aimed towards universal health and social security principles, the Brazilian state still fails in its objectives. This failure not only shapes experiences within peripheral areas but also generates resistance among mothers of children with disabilities to these failures. As such, it shapes disability activism in such contexts. The following chapter will outline the methodology used in the data collection.

Chapter 4 – Research design

4.1. Introduction

The thesis's main aim is to explore how the experiences and actions of mothers of children with disabilities in peripheral communities in Brazil challenge the understanding of disability activism. In addition, the thesis seeks to investigate how mothers of children with disabilities in peripheral areas experience and respond to limited information and service provision, and how their individual and collective actions challenge state neglect in providing adequate care and support. It also aims to bridge the gap between parents and disability activists through a participatory, socially justice-oriented research approach while ensuring the project supports advocacy goals and provides tangible benefits for participants and partners. The methodology outlined in this chapter aims to satisfy the project objectives.

Drawing on Alison Kafer's political/relational model of disability to apply an intersectional feminist Critical Disability Studies perspective, I will examine the experiences and actions of mothers of children with disabilities in Brazil while exploring disability activism. The project also utilises Dokumaci's (2019) theory of microactivist affordances as a framework for theorising mothers' activism and politicising mothering within a peripheral context. This theoretical grounding will form the basis for a qualitative mixed-methods approach that uses abductive methodologies, drawing on existing theory and making new theoretical contributions from empirical data.

Reflexive and critical engagement with the context influenced the participatory approach to the methodology laid out in this chapter. In this project, I understand participatory research to be research designed in negotiation with the community, recognising the plurality of experiences and views about issues relevant to the community, with outputs that can be used by the community and their representative civil society organisations. Consequently, the project partners guided the generation of the research questions and the interpretation of the data. Their input helped to maintain an intersectional and critical approach that considered the perspectives of the research participants but was also grounded in the lived experiences of those living and working in the peripheries. Taking an abductive approach within the project and applying a conceptual framework that makes space for these perspectives, therefore helps to challenge the dominance of Western literature within the area of parents' movements and Disability Studies by allowing previously unexplored themes to arise out of the context of the research.

The PhD study was designed as part of a larger collaborative project, *Projeto das Mães* [EN: the Mother's Project], involving civil society partners, which also considerably influenced the methodology. The collaboration with civil society partners grew out of a previous research

and advocacy project funded by the University of York that I was involved with since 2021, focusing on the intersection between disability and racial discrimination in the Brazilian context. The project partners, Vidas Negras com Deficiência Importam (VNDI), were involved in educational and impact-related activities linked to the project's research component. In addition, the research aimed to collect data to answer the research questions the partner influenced and generate alternative research outputs for the partner's advocacy activities, as discussed in this chapter.

The study design took a qualitative approach, utilising mixed methods that comprised of interviews with professionals, mothers, and civil society representatives, and workshops organised with project partners which included creative data collection activities, and observation of *roda de conversa* [EN: conversation circle] facilitated by the project partners (defined in subsection 4.2.5. on data collection). Drawing on the principles of participatory action research (PAR) that relies on co-production of the research design, data collection and outputs, the study was principally designed in collaboration with the key project partners, linked to a project they had initiated in 2022. According to Klocker (2015, p.3), the *action* element in PAR refers to 'seek[ing] to make tangible, positive changes to the lives of disadvantaged and marginalised individuals and communities.' In this project, the *action* element sought to generate data useful to the ongoing work of civil society partners, such as national and international advocacy focused on policy change. Later in the project, during the fieldwork phase, other civil society partners became involved in the Mother's Project, who also shaped the study during the implementation and action stage. The co-production element of the research was underpinned by the theoretical CDS approach to the study and the wider project, which presented both issues and opportunities that I discuss in the final part of this chapter.

The previous chapter presented the conceptual and theoretical framework that inspired the empirical data collection, based on the fieldwork conducted in Brazil between 2022 and 2023, as presented in the project timeline in Figure 4.1.

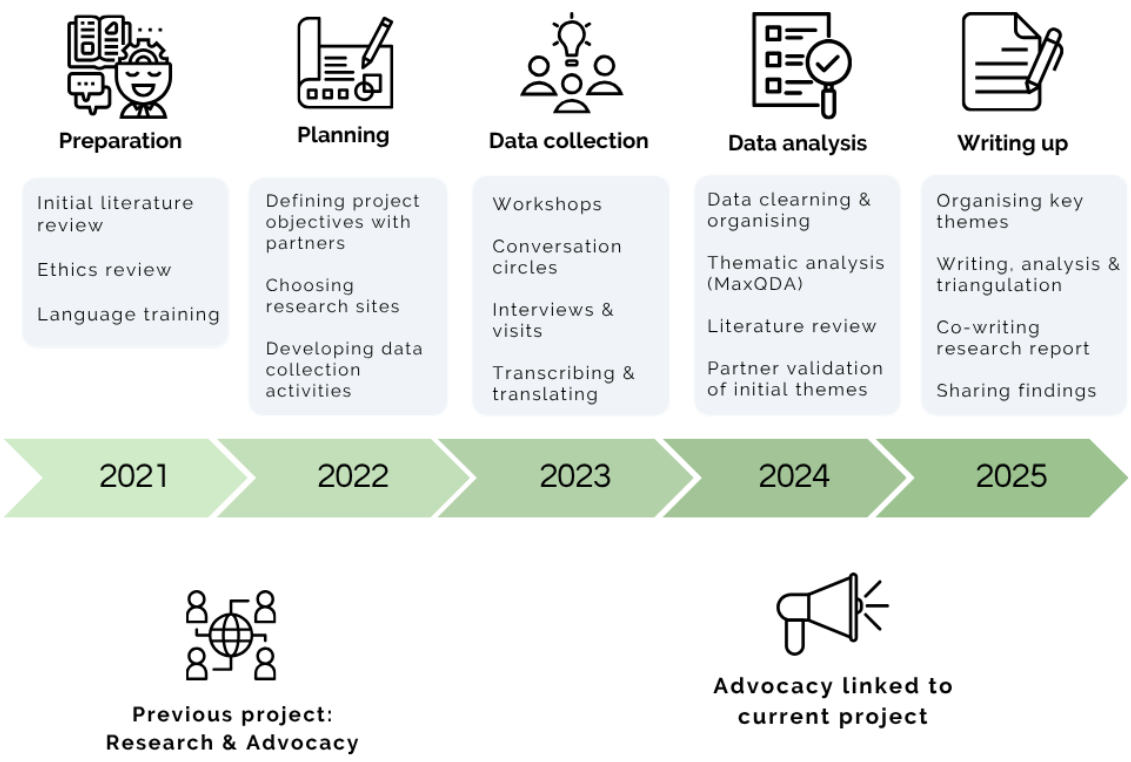


Fig. 4.1. Simplified overview of the project timeline

4.2. Research design

The research approach was rooted in a subjective ontology and a constructivist paradigm influenced by critical theory. A constructivist approach acknowledges the existence of multiple socially constructed realities influenced by the knower's social and cultural context, including language and interactions with others (Kouam, 2024). This approach suggests that language and social interactions influence the experiences and actions of mothers of children with disabilities. Sometimes referred to as a critical constructivist approach, constructivist approaches can be blended with the Frankfurt school's Critical Theory. This approach examines the role of power and social inequality in society by analysing how participants construct their views of reality, considering their social and historical context and what constitutes 'valid knowledge' and why (Coghlan and Brydon-Miller, 2014). As a result, the research design employs a mixed-methods qualitative approach to empirical data collection to analyse participants' meaning formation and triangulate with literature that analyses the social and historical context, as outlined in Chapter Three.

The research paradigm was also embedded in participatory, community-based action research and digital/traditional ethnography methodologies. Participatory research,

sometimes referred to as participatory action research (PAR), is a broad term that encompasses various research frameworks and has its roots in both Northern and Southern traditions of emancipatory philosophy (Macaulay, 2017), such as human rights, collective liberation, social equality and decolonisation. I reflect here that participatory research with groups who have been historically erased can help to avoid epistemicide – the annihilation of knowledge systems - and facilitate knowledge democracy. Knowledge democracy is defined by Hall and Tandon (2017) as the acknowledgement of multiple knowledge systems, multiple forms of knowledge, and the power of knowledge to strengthen democracy and the action of social movements.

Participatory research is employed across almost every research discipline and has varying definitions and applications. However, the most crucial element of participatory research relevant to this thesis is that it engages *with* the communities it is about in the research process. Participatory research has various benefits, including wider application in the real world, influencing policy change, improving research quality and better translation and dissemination to the communities at the centre of the research (Cargo & Mercer, 2008; Vaughn & Jacquez, 2020).

The participatory elements of this research ran throughout the research process, from design to dissemination, and will be expanded on in section 4.2.1 and Fig. 4.2). The project's objectives to use the research for advocacy as part of The Mothers' Project by the civil society partners also influenced the research design, notably the research outputs (see Chapter Eight for more detail). Dissemination of the findings was developed with partners through co-production of a research and advocacy report, submissions to international human rights mechanisms (see section 4.4.2 and the appendix J and K), human rights organisations and funders, to generate funding for project continuation. In this way, the research and advocacy work of the partners supported each other and was a key element of the participatory research process in this project.

The research design relied on an embedded multiple case study approach using ten mothers' networks across four states in Brazil. The mothers' networks, to be presented in section 4.2.3, are listed in Table 4.1, and interviews with professionals from health and social services. According to Thomas, case studies provide highly detailed information about the phenomena to be studied, which gives a multi-dimensional rather than general perspective (2021). Simons further adds that case studies are not methods in and of themselves but are composed of various methods aiming to reveal detailed information about a specific topic (2009). This study intends to add a different perspective to the existing literature on parent activism and disability activism to address a gap in the Global South, as well as peripheral perspectives. A case study approach helps fulfil these aims by providing in-depth information across a limited number of research sites, defined by specific selection criteria to address the research gap.

4.2.1 Participatory disability research

Whilst community-based participatory research is a type of the broader field methodology of participatory research, the former is considered to focus more on the equitable partnership between researcher and community members (Tapp, White, Steuerwald, & Dulin, 2013). Therefore, a participatory disability approach must involve disability community members and their representative organisations throughout the research process, rather than just one part, such as data collection. This approach was important to the design of this project, both to improve the quality of the research and to adhere to the core principle of the disability rights movement of 'nothing about us without us' (Charlton, 2000). In addition, the involvement of mothers of children with disabilities who identified as women with disabilities and disability activists in the team was central to ensuring a balanced perspective and resolving some of the tensions identified in the previous chapters between parents and disability activists.

A participatory approach that devolves control of the research objectives, methodology and outputs to community partners moves away from a scientific positivist epistemology, and supports a constructivist approach. The adjusted power dynamic intends to bring a 'messier' approach to the research design, reflective of the complexities that come with working across academia and civil society in a collaborative and participatory way. I argue then that this messiness is a key feature of participatory research, even though many researchers are not transparent about the realities of the messiness of fieldwork when describing participatory methodologies (Fitzgerald, Stride, & Enright, 2021). Rather than hiding the messy realities of fieldwork, we should embrace the possibilities this brings to expanding the research concept and its applicability in the real world. Indeed, Dancis et al. suggest that using a neat, checklist approach to participatory research risks depoliticising and therefore devaluing it (2023), thus highlighting the value of a 'messy' or organic approach to researching *with* members of communities.

However, a 'messy' participatory approach may also bring limitations to research, including the lack of comparability and difficulties in its application. According to Johnson et al (2020), indicators of academic rigour in qualitative research include clear research questions, a strong conceptual framework, the selection of appropriate research methods and researcher reflexivity. I therefore aimed to mitigate the limitations of 'messy' participatory research as much as possible by following the criteria, as elaborated on in this chapter. At the same time, I was careful not to compromise the necessarily 'messy' and flexible participatory approach. This approach aimed to challenge the power imbalance between me as the researcher and the civil society partners, and to prioritise voices often missing from current literature. In addition, I stress here that the value that the participatory approach adds to the construction of knowledge rather than takes away from academic rigour. In

summary, I felt that it was essential to ensure the research produced data that satisfied the criteria of the research partners first, as well as the requirements of academic rigour.

Participatory research, shaped by the disability rights movement, is central to Critical Disability Studies and often linked to an emancipatory paradigm, which aims to shift control of knowledge production to disabled people and promote empowerment (Oliver, 1997). However, researchers should not conflate participatory research with emancipatory research. Critics argue that claims to emancipatory disability research overlook definitional disagreements within the field, downplay the role of the researcher, devalue other types of research (Meekosha & Shuttleworth, 2009; Humphries, Mertens, & Truman, 2000), and fail to challenge the material resources of research production, including ownership, resources and funding (Oliver, 1997; Zarb, 1992). This critique is particularly pertinent in PhD research, where institutional constraints limit the ability to adhere to emancipatory or participatory research principles.

Limitations and levels of participatory research

According to Stone and Priestly (1996), emancipatory research must transfer ownership and full control to the research participants instead of the researcher; otherwise, it is only participatory. Though emerging in the Global South and low-income contexts such as Brazil, participatory disability research is achievable, potentially impacting policy and producing quality research (Kuper et al., 2021). However, there are also different levels of participation available at each stage of the participatory research process, which Vaughn and Jacquez (2020) conceptualise as 'choice points', ranging from informing the community of the research to empowering the community to lead research. In acknowledgement, this research applies a participatory approach as far as possible within the constraints of a PhD project. In line with the participation points suggested by Vaugn and Jacquez (2020), the participation level for this project is indicated by the green stars in Figure 4.2, taken from their work. Whilst the participation level ranges from consultation to collaboration at various stages, the participatory approach enabled the co-production of research outputs for practical impact for people with disabilities and their families in Brazil beyond the thesis.

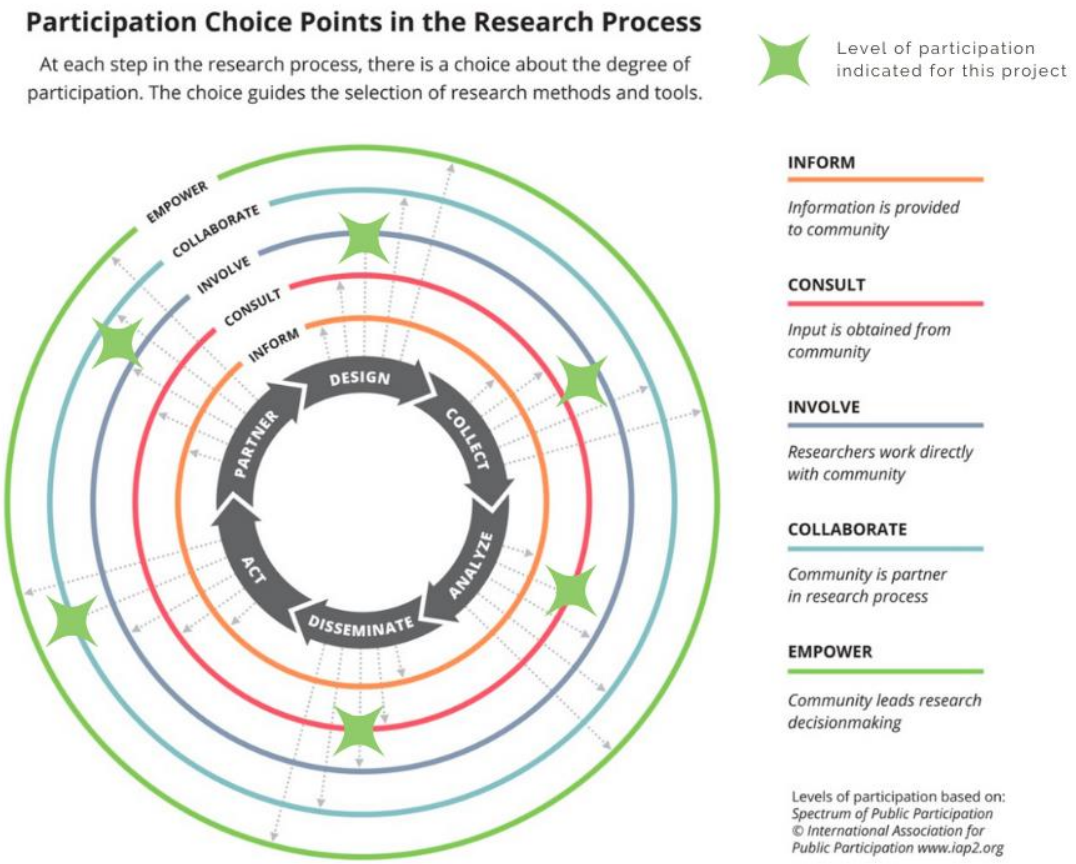


Fig. 4.2. Levels of participation for this project indicated on Vaugn and Jacquez's diagram of Participation Choice Points in the Research Process, 2020.

Applying a participatory research approach within a PhD project is difficult for various reasons. Millora, Maimunah and Still reflect that whilst doing PhD research in the global south but based in global north institutions, aligning with institutional ethical and bureaucratic requirements reproduces historical power imbalances and limits the potential for students to undertake ethically situated research (2020). Seymour and Garbutt (1998, p. 3) elaborate, pointing out that the participatory view of research 'contradicts with the view of the expert researcher prevalent within higher education establishments, and particularly within the individualised construction of research degrees, which requires a thesis to be the exclusive product of one individual'. I reflect that whilst the participatory nature of the thesis was limited by the constraints of the PhD programme, the linking of the PhD project to a broader project led by civil society has enabled greater participation at the dissemination and 'act' stages of the research, allowing for greater ownership and impact of the research findings, which will be further touched on in Chapter Eight.

Participatory research with community and civil society

Participatory research can only be achieved through ongoing and non-hierarchical dialogue between the researcher and the community members (Glassman & Erdem, 2014). In this case, the community primarily consists of mothers of children with disabilities - the leading target group for the research - as well as people with disabilities and other family members involved in their support networks. Acknowledging tensions between parents and people with disabilities in academia and activism, as previously outlined, the methodology was shaped through ongoing dialogue with civil society partners— people with disabilities and mothers of children with disabilities—between 2022 and 2023. Through these ongoing dialogues, the project aimed to follow a participatory framework (see fig.4.2) in collaboration with civil society organisations during the research design, data collection, analysis and output generation and dissemination, including advocacy, which continued throughout 2024 and 2025.

Paulo Freire's work, particularly *The Pedagogy of the Oppressed* (1970), has influenced the development of participatory research by bringing Marxist ideas to the methodology and moving away from individualism, favouring individual action, privacy and self-reliance over collectivism and society. This influence is significant in societal contexts where collective values are higher and more focus is on benefits for the wider society, including those most vulnerable. For example, Freire's approaches have been widely applied in the development sector, education and research to generate community-led policies and solutions (Macaulay, 2017). Freire has also influenced Brazilian civil society's bottom-up approaches, such as participatory dialogue and connecting civil society groups around common goals (Suzina, Tufte, & Jiménez-Martínez, 2020). The participatory dialogue approach can be helpful in connecting mothers and people with disabilities around common goals: for example, identifying the wider structures of oppression which link their struggles through Paulo Freire's (1970) key concept of *Conscientization* - the process of critical reflection on the larger social systems that define their lives and of their ability to change actions in resistance of this (Glassman & Erdem, 2014). This philosophy shaped the participatory and creative activities described in subsection 4.2.7.

As outlined in the literature review presented in Chapter One, more recent attempts have applied participatory research methodologies to research with caregivers of children with disabilities (see Adams & Galvaan, 2010; Araújo, 2011; Kuper et al., 2021). However, the majority of this research does not engage wider civil society. This omission raises the question of how sustainable the research impacts can be, considering the barriers that women caregivers in marginalised settings face to engaging with and enacting advocacy (Adams & Galvaan, 2010) and the exclusivity of the mainstream disability rights movement. Additionally, this thesis evolved out of the recognition of the research gap that excludes the perspectives of women with disabilities who are also mothers of children with disabilities,

and their contributions to both parent activism and disability rights activism in marginal contexts.

Context for the collaboration with civil society partners

The study's central collaboration was with the civil society group Vidas Negras com Deficiência Importam (VNDI) and networks of mothers of children with disabilities with whom they were linked as part of The Mothers' Project. As noted, the civil society partner, VNDI, had previously partnered with me on a research and advocacy project at the University of York using the UN human rights mechanisms to address race and disability discrimination in Brazil (Minority Rights Group, 2022). Through this collaboration, VNDI invited me to link my doctoral research to The Mothers' Project, which focused on supporting mothers of children with disabilities with rights-based, intersectional information from anti-ableist, anti-sexist, and anti-racist perspectives. Therefore, the research was influenced by this initiative's aims to help the civil society partners better understand the barriers that families with children with disabilities faced in peripheral areas and how networks of mothers helped to facilitate access to information and support.

The core project team consisted of VNDI members, me, and their partners in The Mothers' Project, including one mother-leader of a network in Bahia. A significant amount of input came from VNDI's director, Luciana Viegas and Maira Cavalcante, who was involved in The Mothers' Project with VNDI. The unique perspectives of Luciana and Maira as Black/*parda* women, mothers of children with disabilities, and women with disabilities influenced the design of this research, from conceptualisation of the aims of the project, the data collection methods and data collection through to dissemination and use of the data for advocacy. However, other women with disabilities, members of VNDI, were also involved at various stages of the research. This model reflects other participatory research projects that have used an advisory committee of community members to provide input and feedback on the project design and implementation (Mesiäislehto, 2023; Seymour & Garbutt, 1998). VNDI also helped with recruitment and data collection, organising the workshops where data collection activities occurred.

A Brazilian public research institution was also involved in the research - Fundação Oswaldo Cruz (Fiocruz) - under the Ministry of Health. Researchers from Fiocruz supported the project via my Brazilian supervisor and her postdoctoral research team based in Minas Gerais, and a separate research team based at Fiocruz Rio de Janeiro, who helped support and recruit for the workshop in Rio de Janeiro. In addition, these teams gave feedback, assisted with the Brazilian ethics procedure, helped to recruit participants via their networks, and provided space for workshops.

The participatory research process with project partners was long and complex, requiring careful power-sharing and the development of a 'common language' (Tiffany, 2006, p. i115). This was achieved over time and formalised through a partnership agreement with two mothers closely involved in the research. The agreement outlined roles, data collection and ownership, anonymisation, access, compensation, and travel arrangements (see Appendix A). The team secured funding from the University of York to cover compensation, workshop costs, and domestic travel. The budget was co-developed with partners, who provided locally sourced estimates. From January to May 2023, the team held eight two-hour planning meetings via Google Meet. All materials, notes, and documents were produced in Portuguese and stored on a shared Google Drive accessible to core team members.

4.2.2. Positionality and power

Doing research on a 'Global Development PhD' programme based at a university in the global north presents multiple challenging and ethical issues, both in terms of navigating bureaucratic institutional processes, such as ethics review, and in terms of the implications of the power relations produced and reproduced through the process. This also includes links to the identity and positionality of the researcher, which makes interrogation of my positionality as the researcher essential. In this section, I attempt to lay out the complex dynamics of power stemming from interactions between myself, the institution, the project partners and the research participants whilst drawing on how other scholars have attempted to deal with similar dynamics in social justice research. However, I do not claim the ethical issues that arise can, were, or should be 'resolved' during the research project. Instead, I aim to explore this topic to be as transparent as possible about my experience, including discomfort and acknowledgement of my complicity, shifting subjectivity, struggle and resistance to the complex processes of positionality and power throughout the research.

Davis and Walsh (2020) explore how a researcher's epistemic stance is shaped by their social position and identity, comparing anti-colonial, decolonial, and postcolonial perspectives, particularly those of Spivak, Ahmad, and Mignolo. They contrast postcolonial scholars' emphasis on textual reflection and complicity with decolonial scholars' focus on praxis and political engagement. Ultimately, they warn against two extremes: denialism, the idea that identity has no influence; and, reductionism, that identity is the sole influence. I suggest that their middle-ground position encourages researchers to be self-reflexive about aspects of identity and positionality, some of which are fixed and others chosen, while also emphasising responsibility for our praxis, drawing on a Marxist understanding of linking theory and action for political and social change.

Researcher Self-reflexivity

Praxis in social justice research should be guided by continual self-reflexivity—a core idea in Paulo Freire's (1970) vision, which calls for ongoing self-examination. Influenced by feminist and critical theories, self-reflexivity aligns with the constructivist epistemology of this research and is central to qualitative methods. Self-reflexivity, therefore, involves awareness of self-identity, accountability, risk and ethical obligations (Giddens, 1991; Bos, 2020) and recognition of reflexivity as a reciprocal process in which the researcher and research shape each other (Attia and Edge, 2017). Reflecting on my position—as both researcher and someone with shared and differing experiences from participants—can help address power imbalances. However, I challenge the assumption that such reflection alone can fully resolve them.

Critics such as Jen Rinaldi (2014) and Wanda Pillow (2003) warn that uncritical or self-serving practices of reflexivity can risk moving away from the emancipatory aims of disability research or even 'othering' the subjects of the study by centring the experiences of the researcher instead of the research participants. Pillow's (2003) concept of 'self-reflexivity' has arisen from critiques of colonising approaches to research, and reframes self-reflection not as a route to legitimacy, but as an ongoing critique of the research process itself, acknowledging both the need to represent and the impossibility of fully capturing lived experience. By uncomfortably interrogating the privilege and power I hold about my 'shared experiences', I interrogated the power dynamics shaped by my positionality and identity, as outlined in the introduction.

Power and positionality

I reflect on the complexity of my positionality about participants and project partners, aligning with critiques of the simplistic insider/outsider binary (Millora, Maimunah, & Still, 2020; Sherry, 2016). Although seen as an outsider due to my status as a foreign researcher, participants sometimes challenged this view and identified me as part of *a luta* [the struggle]. For instance, during an interview with mother leaders in Rio de Janeiro, I was questioned about my motivations, only for a participant to affirm, "You are still in the struggle because you have brothers and sisters for whom you are, in a way, a caregiver." This aspect of my identity helped me gain trust and access that might not have been possible otherwise. However, shared experience does not negate my power and privilege, nor does it mean I can fully understand participants' lives. A critical, self-reflexive approach—supported by fieldnotes and regular dialogue with supervisors, partners, participants, and colleagues—was essential to navigating ethical challenges and power

imbalances. This process was one of the most difficult aspects of the PhD and remains unresolved.

Power dynamics within the core research team also required attention. Buettgen et al. (2018) emphasise reflexivity to develop self- and role-awareness, question power and privilege, and challenge assumptions. Following their suggestion to begin by questioning foundational concepts, we opened the project with partner-requested activities asking participants, “What is disability?” and “How has disability impacted your life?”—prompting us to confront our assumptions, despite shared intersectional and rights-based views. Ongoing conversations with partners around ethics, care, and researcher responsibility led to meaningful changes in the research design, such as creating an evaluative questionnaire (see subsection 4.5), adapting methodology, and jointly evaluating the project. We also addressed the fieldwork's emotional and physical toll, leading to the cancellation of a planned workshop in Minas Gerais to allow space for rest and reflection before continuing with the workshops in São Paulo and Rio de Janeiro.

Complicity

A second key issue concerns conducting research from within a British higher education institution that, while promoting itself as internationally engaged and committed to the public good (University of York, 2023), is also complicit in upholding racist, ableist, and sexist systems. This contrasts sharply with the Brazilian research context, shaped by the legacies of settler colonialism and the transatlantic slave trade systems in which British institutions played a central role in constructing what Mignolo (2011) calls the ‘colonial matrix of power’. By acknowledging this, it does not mean that meaningful research is not undertaken within research institutions, but it is important to highlight the contradictions they embody and the ongoing resistance from students, staff, and communities. As a beneficiary of UK higher education, I acknowledge my complicity in these structures while recognising the potential to resist from within. Engaging in such resistance by participating in anti-racist initiatives, challenging my university and government to divest from technologies and finance being used in the oppression and genocide of the Palestinian people, and pushing for the inclusion of Critical Disability Studies in the curriculum are also actions that I see as linked to my ongoing work and commitment to praxis.

4.2.3. Cases: Mothers’ networks

The embedded multiple case study included participants who were members of ten different mothers’ networks across a total of four research sites in four states (see Fig. 4.3). Data was collected in multiple and overlapping ways owing to the opportunistic sampling approach and the participatory nature of the research design and data collection with civil society partners. Workshops were conducted across three research sites: Bahia, São Paulo

and Rio de Janeiro, and interviews were conducted across all four research sites, including Minas Gerais. Seven conversation circles took place at workshops run by the project partners, and an additional conversation circle in São Paulo took place at a mothers' network, separately from a workshop. A total of forty-six participants took part in the conversation circles, and forty-one in the workshops. Seventy-seven people filled out the online survey ahead of the workshops and conversation circles, from which the demographic participant data is derived, to be presented in the following chapters. Therefore, thirty-six people enrolled in workshops but did not turn up on the day.

Representatives from at least eight mothers' networks attended conversation circles and workshops, although it is noted that some mothers were affiliated with more than one network. Mother leaders were interviewed from two other networks, but their members did not participate in the workshops, bringing the total number of networks represented in the research to ten. Networks are listed in the table below, anonymised where necessary to protect the identities of workshop participants.

Network Number	**Network Description**	**State**	**Method of data collection**	**Network description**
Network 1	*Autism*	*Bahia*	*Conversation circle, mother leader interview (1)*	*A network for mothers of Autistic children, founded by a mother with disabilities and other mothers without disabilities. There is no physical space, but meetings are occasionally organised in person. Communication is via WhatsApp and social media.*
Network 2	**Abraço Microcefalia** - *Children with CZS*	*Bahia*	*Mother leader interview (2), visit*	*Network of over 330 families of children with CZS. Physical space with regular events and some services provided, including physiotherapy. Has a website and social media presence.*
Network 3	*Autism*	*Bahia*	*Conversation circle*	*This is a network for families of Autistic people. It has a physical space, regularly runs workshops and events, and provides some services. It communicates via WhatsApp and social media.*

Network 4	**Projeto Marias** - *All disabilities*	*Rio de Janeiro*	*Conversation circle, mother leader interview (4), visit*	*Network of families with children with disabilities. Has a physical space in the Manguinhos complex, regularly runs educational activities for children & parents. Communicate via WhatsApp and social media.*
Network 5	**Anjos de Minas** *Children with CZS*	*Minas Gerais*	*Mother leader interview (5)*	*A network of around 70 mothers of children with CZS. There is no physical space, and the network does not meet regularly owing to distance and issues with accessible public transport. It communicates via WhatsApp and social media.*
Network 6	*Autism*	*São Paulo*	*Conversation circle, mother leader interview (6)*	*A network of parents of Autistic children who have organised to lobby the local government to make changes to the school and health system. The network has no physical space but communicates via WhatsApp and social media.*
Network 7	*All disabilities*	*São Paulo*	*Conversation circle, visit*	*The mothers' group was established at a centre (clinic-school) that served several municipalities. Has a physical space on-site. Runs craft and other workshops and has a bazaar selling second-hand clothes to raise money for the centre.*
Network 8	*All disabilities*	*São Paulo*	*Conversation circle, mother-leader interview (6)*	*A network of parents of children with disabilities that functions via WhatsApp. No physical space or social media presence.*
Network 9	*All disabilities*	*Rio de Janeiro*	*Conversation circle*	*Network of parents of people with disabilities. Has a physical space with a community wardrobe for second-hand items.*

				Communicate via WhatsApp and social media.
Network 10	*Down Syndrome*	*Rio de Janeiro*	*Conversation circle*	*A network of families who have children with Down syndrome. No physical space, but organise regular events and meet-ups. Communicate via WhatsApp and social media.*

Table 4.1. Mothers' networks

Most of the networks included in the study were formally registered with the Brazilian National Registry of Legal Entities (CNPJ) as private associations. Many networks remained largely virtual, especially during and after the Covid-19 pandemic, and limited to digital communication between members. However, some registered associations operated more like NGOs, either providing social, healthcare or educational services by directly employing professionals such as social workers, psychologists or physiotherapists or facilitating service provision provided by local professionals working voluntarily. Associations generally relied entirely on donations from their members or the public to fund activities or support members who were experiencing financial difficulties.

4.2.4. Data collection sites

Figure 4.3. Map of Brazil showing the four research sites.

The case study sites were selected in collaboration with project partners, aligning with the project's participatory approach. Drawing on partners' civil society networks and my connections through Fiocruz, we chose a range of community networks of mothers and carers of children with different types of disabilities—some impairment-specific, others mixed. All selected sites were located in the *periferias* [EN: peripheries]—lower-income areas such as favelas or *comunidades*[6] [EN: communities], where families are predominantly from lower socio-economic backgrounds, largely identify as Black or *pardo*, and typically rely on public services. This opportunistic yet intentional approach reflects participatory research's complex, flexible nature with community partners.

[6] *Sometimes used to refer to* favelas *or other peripheral, typically low-income urban zones.*

Salvador, Bahia

The first research site was in Salvador, Bahia state, Northeast Brazil. Salvador was the first colonial capital of Brazil from 1549 until 1763, where it was Brazil's main port and centre of the slave and sugar trade. The city has remained the largest city in the northeast, important owing to its port and historic significance, which led to its being designated as a UNESCO World Heritage site in 1985. The northeast, which encompasses the nine states of Alagoas, Bahia, Ceará, Maranhão, Paraíba, Pernambuco, Piauí, Rio Grande do Norte and Sergipe, is known both for its history as the first area to be colonised by Europeans and for the struggles of resistance to colonisation by Indigenous and enslaved African peoples. The region is valued for its rich culture, including regional dialects, food, art, and music, which is influenced by Indigenous and African cultures and its history of colonial resistance.

The northeast is also the driest and poorest area in the country, accounting for the highest rates of poverty and extreme poverty (43.5% and 54.5% of all cases, respectively); the highest rates of unemployment and underemployment, and the second highest rates of informal work (IBGE, 2023b). In 2023, Bahia state had the lowest average monthly salary in Brazil (IBGE, 2023b). The high rates of inequality in the region can be directly correlated to skin colour/racial category; the northeast has the highest population self-identifying as black and the second highest population self-identifying as *pardo,* considered as the most 'vulnerable groups' in relation to inequality and poverty measures and particularly amongst women and youth (IBGE, 2022). The northeast region also has the highest rates of registered disability, at around 5.8 million people or 10.3% of the total population of people with disabilities and the highest rates of children with disabilities (IBGE, 2023a). Amongst the population of people with disabilities, the northeast has the highest rates of illiteracy, unemployment, the lowest rates of education and the lowest average wages, as well as the highest wage inequality between people with and without disabilities (ibid). The socioeconomic situation of the northeast region concerning gender, disability and race identities is therefore relevant, yet often overlooked in the analysis of disability in policy and academic debates.

Belo Horizonte, Minas Gerais

The second research site was in Belo Horizonte in Minas Gerais, in the Southeast of Brazil, in July 2023. A workshop was initially planned to take place here. However, as described earlier, the project team decided to cancel the workshop because of the psychological and physical toll of the data collection and logistical issues in organising a workshop there. Mother leader five was instead interviewed to provide insight into the network. However, the limitations of this approach are noted, owing to the lack of data collected from other

network members. This was a network of mothers of children with Congenital Zika Syndrome (CZS), called *Anjos de Minas* [EN: Angels of Minas], established in 2017 to link mothers of children with CZS via WhatsApp groups.

São Paulo

The third research site included two neighbouring municipalities of São Paulo, located in the North of the state of São Paulo, in the southeast region of Brazil. The southeast comprises the four states of Minas Gerais, São Paulo, Rio de Janeiro and Espírito Santo, with a tropical climate and diverse geographic terrain. It is the most populated region, with most of this concentrated around the larger cities of Rio de Janeiro, São Paulo, and other smaller towns. The southeast occupies a better socioeconomic position than the northeast, with the second-highest household income average per capita after the south (IBGE, 2023b). Skin colour/racial category composition of the population is primarily white (49.9%), followed by *pardo* (38.7%), black (10.6%), yellow (0.7%) and indigenous (0.1%) (IBGE, 2022). Registered disability rates in the southeast are the lowest nationwide at 8.2% but still comparable to the north, central-east, and south at 8.4%, 8.6% and 8.8%, respectively (IBGE, 2023a). Regionally, the level of education and participation in the job market for people with disabilities in the region was comparable to the overall average for Brazil. Still, literacy rates and average income are higher than the national average (ibid).

Manguinhos, Rio de Janeiro

The third data collection site was in Rio de Janeiro, another state in the Southeast region of Brazil (as described above), a vibrant coastal city mainly known for being a popular tourist destination owing to its stunning natural landscapes, famous beaches, iconic landmarks and rich cultural heritage. It has a diverse population, differing slightly from the regional average listed above. According to the Census, the population of Rio de Janeiro city is identified as Black at 51.7% and white at 47.4% (IBGE, 2010). Rio de Janeiro is characterised by deep inequalities - known for glamorous beaches and houses of the rich and famous, whilst also housing some of the world's largest favelas, including Rocinha and Manghuinhos, where workshop five took place. According to WikiFavelas (2025), Manghuinhos has high rates of violence and drug trafficking, and poor sanitation and infrastructure, despite various investments and urban planning projects that have aimed to make improvements.

4.2.5. Participant sampling and recruitment

Professionals

Professionals were included in the participant sample to get a different perspective on mothers' experiences and access to information and services. The sampling framework included healthcare professionals who either managed or worked directly with families of children with disabilities and leaders of community support networks. A combination of purposeful, opportunistic and convenience sampling was used to recruit professionals as interview participants. One municipal manager responsible for people with disabilities was also included via opportunistic sampling during fieldwork. Most health and social care professionals who participated in interviews were recruited via the personal contacts of myself and project partners. See Appendix G for the interview schedule.

Mother-leaders

Mother leaders were identified via existing networks of partners and Fiocruz, except for two mother leaders who enrolled in workshops. Six mother leaders of Mothers' Networks were recruited via opportunistic sampling. Two mother leaders participated in conversation circles during workshops, and the other four were interviewed separately.

Mothers - participants

For mothers, a participatory approach to purposeful sampling was used to select participants based on the sampling framework developed with the project partners during the planning stage. As previously outlined, participants were drawn from the '*periferias*' [EN: peripheries], and the project partners identified community network members. A participatory approach to sampling and recruitment involving the project partners, who are community members, has been noted to help increase community engagement and resolve power dynamics between the community and the researcher (Tiffany, 2006).

Mothers were recruited via written invitation in the workshop enrollment form. The form and participant information sheet were distributed by the project partners and local partners via their existing community networks, via email, within private WhatsApp groups, or via their social media pages. The partners, therefore, had a role in acting as gatekeepers to the target community via their existing networks, which helped shift power to the project partners in recruitment decision-making.

4.2.6. Informed consent

Obtaining informed consent is a critical component of ethical research, defined in this study by two key elements. First, participants must receive sufficient and accessible information about the research, the research team, and the implications of participation. Second, they must be able to make an informed, uncoerced decision about the risks and benefits involved. Krogstad et al. (2010) highlight the ethical complexities of securing informed consent in international contexts, including cultural variations in individual versus collective decision-making, oral versus written communication, and the challenges of translating materials across languages. As a foreign researcher, these issues were particularly relevant, making consultation with project partners vital to ensure a culturally appropriate and ethically sound process.

Contextualising informed consent within the specific Brazilian research setting helped navigate these challenges. The concept, imported from Western frameworks, entered Brazilian legal discourse through the regulation of doctor-patient relationships, including rulings by the Superior Court of Justice (de Sá Lima & Rocha, 2023). While similarities existed between the ethical requirements of the University of York and Brazil's National Commission in Research Ethics (CONEP), cultural differences remained, even within Brazil. As such, a flexible, inclusive, and collaborative approach was essential. Adopting a disability-inclusive methodology and working closely with local partners addressed ethical concerns, particularly for participants who were illiterate or had intellectual disabilities. Consent materials were repeatedly revised for clarity, read aloud when needed, translated into Portuguese with input from native speakers, and an Easy Read version with simplified language and visuals was prepared, though ultimately not requested.

Interviews

For interviews conducted on Zoom, participants were sent the participant information sheet beforehand and asked to sign a consent form and return it via email or WhatsApp prior to the interview. I also checked with participants again that they consented to audio recording before starting the interviews and offered a written transcript to be sent back to the participant for review. For interviews conducted in person, a similar process was followed, whereby the participant was given time to read the information sheet and consent form, and any questions were answered.

Workshops and Conversation Circles

For the conversation circles, a double process of informed consent was used to ensure that participants were informed of the research element of the project during the recruitment to the workshops and again on arrival. The double consent process allowed participants to understand the research project before participating in the workshop and confirm this

consent in person. It also allowed the project team to prepare for access requirements and answer any questions. The workshop enrolment form (see Appendix I) included a statement about the research purpose of the workshops and presence of the researcher, a link to the participant information sheet (see Appendix D) and an initial consent form, to ensure that participants had read the participant information sheet before they enrolled in the workshop.

As participants arrived, I introduced myself, explained my role, and provided the participant information sheet, remaining available to answer questions. Most inquiries were informal—about me, the UK, or my Portuguese—while only a few focused on the research. At the start of each workshop, the partners welcomed participants. They introduced me, after which I gave a brief overview of the research aims, our collaboration, and how the data would be used for my thesis and their advocacy. Consent forms were distributed and explained in detail, with support from partners to clarify terms like anonymity using examples. I then checked in with each participant individually to offer help and answer any additional questions.

Audio-recording

Conversation circles were recorded directly onto my laptop via a connected boundary microphone, which I showed participants during the informed consent process. Consent for audio recording the conversation circle was double-checked at the beginning of each session, and I reminded participants that the recording could be stopped and restarted at any point. One participant at the focus group in Rio de Janeiro took up this offer.

4.2.7. Methods of data collection

Workshops

The research activities took place at five workshops co-designed with the project partners, and visual creative methods were used to facilitate the data collection. In addition, the project partners collected optional anonymous demographic information via an online survey included in the workshop enrolment form. They shared the data analysis alongside the qualitative data collected during workshops. Workshop activities included community network presentations, service access mapping, and conversation circles, followed by a training provided by the main project partners, VNDI, to be presented in detail below. Visual methods do not necessarily produce products containing research data; they facilitate dialogues, create inclusive spaces, and build relationships and trust (Lewin & Shaw, 2022). Visual methods were used in this project to support inclusive participation, particularly for those facing barriers to written or spoken expression, such as people with disabilities or

those who are illiterate. These methods facilitated dialogue, storytelling, and reflection, helping create a more accessible and supportive space, complementing the conversation circle method.

Children were present at workshops to allow mothers with no other childcare option to participate. Partners organised onsite childcare, employing trained teaching assistants using the workshop budget. While children were onsite, they were engaged in activities in a separate room and so were not present for conversation circle or workshop activities, other than occasionally checking in with their mothers. Breakfast and/or lunch, drinks, and snacks were provided for everyone in attendance.

Workshop 1 & 2: Salvador

Most participants were residents of Salvador or the neighbouring municipality of Lauro de Freitas and members of networks one and three. The workshop took place at the property of one of the network's members. Two workshops took place, split across two days: Saturday and Sunday. A morning and an afternoon group formed, which crossed over at lunchtime. The separate groups and half-day schedule were decided in consultation with the project partner and participants based on everyone's best availability.

Workshop 3 & 4: São Paulo

The workshop took place in a building rented by the local partner. Two separate full-day workshops were held on Saturday and Sunday, meaning there was a Saturday group and a Sunday group that did not meet. Only one participant was a member of existing networks of mothers of children with disabilities, and she agreed to give a follow-up interview about this network via Zoom.

Workshop 5: Rio de Janeiro

The workshop took place on the Manguinhos Campus of Fundação Oswaldo Cruz (Fiocruz), located in the North of Rio de Janeiro city. The workshop took place on a Friday, when another event took place with mothers of children with disabilities. It took place in a seminar room at the Escola Nacional de Saúde Pública Sérgio Arouca (National School of Health Policy), part of Fiocruz, one of the project partners.

Community network presentations

The community network presentation activity was used only at the Bahia workshops, where participants were members of existing community networks. This activity was based on a participatory creative approach and was developed to answer the research sub-questions

relating to the roles of informal community support networks. Namely, sub-question one: *How are mothers' experiences of children with disabilities shaped by information and service provision in peripheral areas?* Sub-question two: *How do mothers' individual and collective actions address/resist failures of the state to provide disability information and support in peripheral areas?*

This activity was only used during the workshops in Bahia because this was the only location where members of the same existing network participated in the same workshop, giving time for the activity. Participants were split into groups of around 5-7 and provided with paper, coloured pens and coloured plasticine. The aim of providing the different materials was to facilitate the participation of everyone equally and encourage expression that was not limited to words. Other research shows that using arts-based methods such as drawing during focus group discussions aids in the engagement of participants, minimises power imbalance between researchers and participants and allows many different perspectives and opinions to be accessed through the research (Lewin & Shaw, 2022; E. A. Marshall, 2019; Patterson, Markey, & Somers, 2012).

Participants were prompted with two questions, previously agreed on with the project partners: 1) What is [network name]? 2) What is the objective of [network name]? The groups were given around 20-30 minutes to discuss and present their answers. Most of the groups used both words and imagery to answer the questions. Still, each group took a slightly different approach, demonstrating the flexibility that creative methods can bring, whilst producing rich visual and textual data. Groups were then asked to present their group's answers to the questions to the rest of the participants and the research team. The visuals were then photographed and triangulated with the recording of the group presentation and other data, including public social media pages of existing networks.

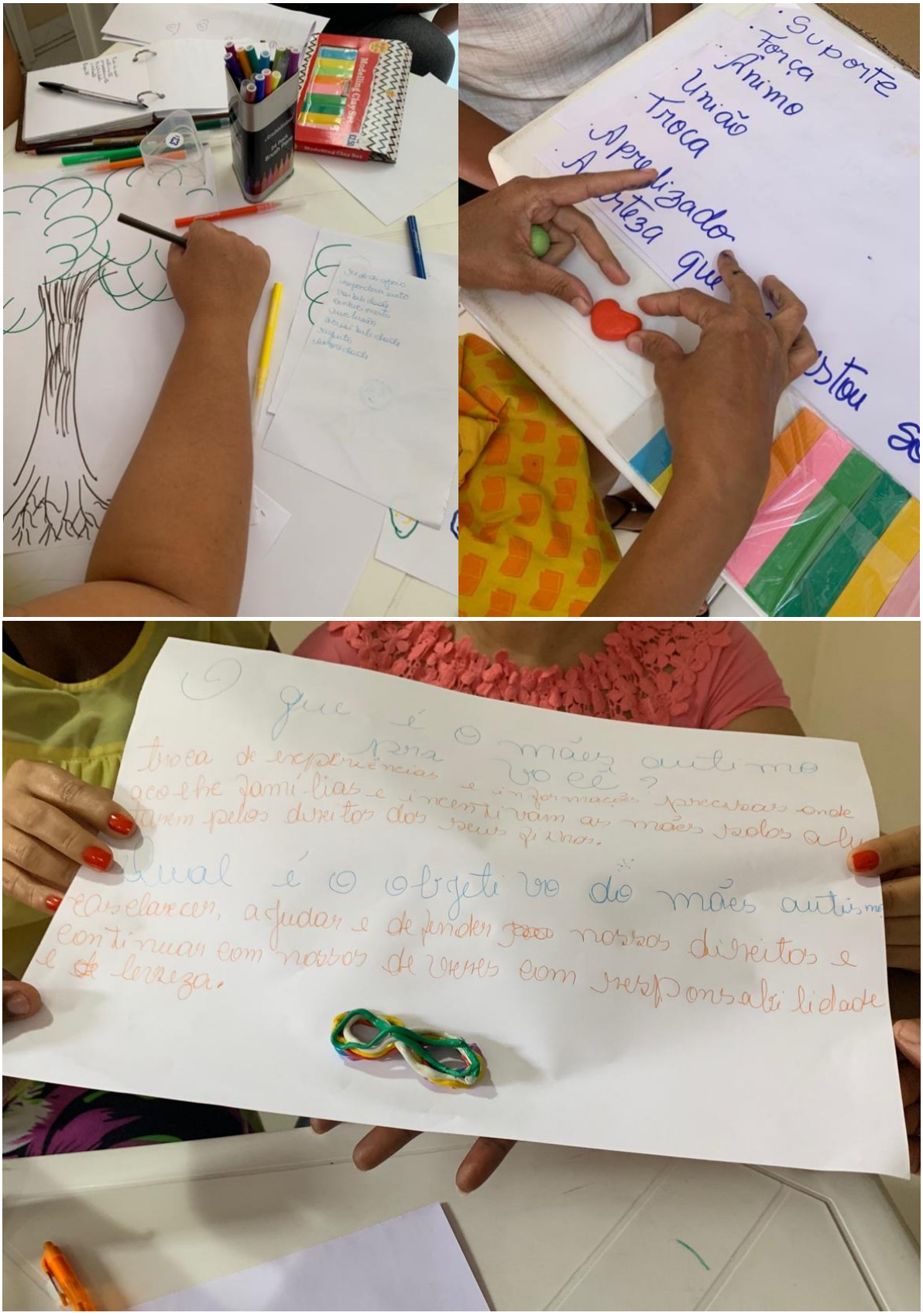


Photo 4.1, 4.2, 4.3. Photos of the participants engaging in and presenting their community network

Access mapping

The access mapping activity was designed to explore how mothers' experiences of raising children with disabilities in peripheral areas are shaped by access to services, support, and information. Inspired by the situational mapping used in the project *This is Not an Atlas* (Orangotango, 2022), I presented this method to project partners during the design phase, where it was adapted for our specific context. Participants first mapped their children's access, prompted by examples such as education, healthcare, therapies, transport, and leisure, and then mapped their own access, including support services and employment.

This separation was crucial, as many mothers were unaccustomed to reflecting on their own needs apart from their children's. Encouraging them to identify personal access needs helped centre their experiences as individuals, not just caregivers. The activity was followed by a conversation circle, which provided space for deeper reflection on navigating systems of support, services, and information.

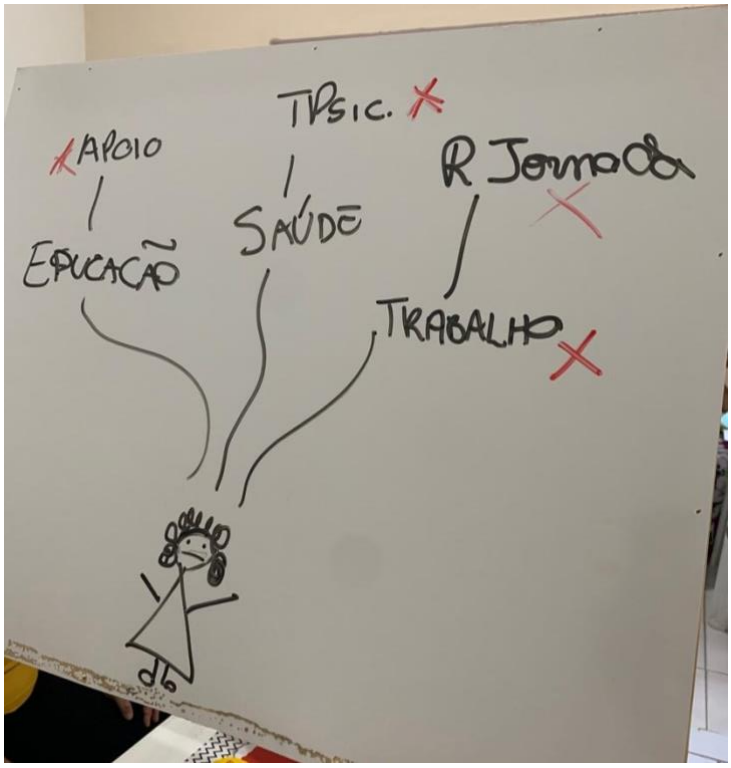


Photo 4.4. Access mapping demonstration

Conversation circles and observation

Eight conversation circles were held across the research sites: four in Bahia, one in Rio de Janeiro, and three in São Paulo. In Brazil, a *roda de conversa* [EN: conversation circle] is used widely in community and adult education to subvert hierarchies within the classroom

between teacher and students. Inspired by Freirean pedagogy, *roda de conversa*, alongside *círculo de* cultura [EN: culture circles], are claimed to be tools for historically excluded communities' political and social liberation (Oliveira, 2021). Conversation circles (sometimes called sharing circles) differ from focus group discussions in several ways. Firstly, they flatten the power hierarchy between the participants and the facilitator by placing them as equals in the circle; secondly, they focus on creation of safe space and solidarity between participants rather than the research aims; and thirdly, they tend to be longer as they allow participants to share for as long as they want to (Tachine et al., 2016).

The use of a conversation circle was employed in the research design through consultation with the project partners, to allow 'for a greater exchange of information, enabling fluid speech and diverse negotiations between researchers and participants' around the research topic (Méllo, Silva, Lima, & Di Paolo, 2007, p. 30). Although conversation circles have only been relatively recently discussed as an academic research methodology, the use of conversation as a research methodology is far from new. Indigenous scholars in Canada have addressed the conversational method as a methodology rooted in the Indigenous paradigm and the long tradition of storytelling (Kovach, 2010; Wilson, 2001). Indigenous conversation methodologies have been employed in participatory research, sometimes blended with Western focus group methodology for more culturally appropriate and impactful participatory research on indigenous peoples' health in North America (Hunt & Young, 2021). Likewise, storytelling has been employed as a research methodology informed by feminist and critical race theory to value experiential knowledge devalued within academia (Yosso, 2005). Observations and recordings of conversation circles facilitated the data collection, without interrupting the flow of the circles.

Observation of training by project partners

Observation included the conversation circle and the *formação* [EN: training] element of the workshop that the project partners gave. The training took place at the end of the workshop, after the conversation circle and other data collection activities, so as not to introduce bias into the data collected. The training included information about the disability rights and racial justice movements and representation within those movements, information about disability rights and laws in Brazil and discussions about ableism, racism and sexism and links between the experiences of people with disabilities and women caregivers. The training usually formed a small workshop element lasting one hour or less.

Photo 4.5. Conversation circle

Interviews

Semi-structured interviews were included in the research project to collect additional insight into how mothers access information, services, and support, as well as the role of information community networks from outsider and insider perspectives, including interviews with professionals that provided better oversight of the information and services available for children with disabilities. Insider perspectives from mother leaders also gave insight into how networks operated and how they emerged. The research was designed to be consistent with recommendations of 9-17 interviews or 4-8 focus group discussions (in this case, conversation circles) to reach saturation in qualitative research (Hennink & Kaiser, 2021). A total of ten interviews were conducted and included two psychologists, both in services for children with disabilities, one private and one public; one service manager and one social worker who worked in public-private partnership services; one municipal manager; five with leaders of mother's networks (see interview schedule in Appendix G).

A mixture of in-person and online interviews was used, due to availability, proximity, or preference of participants, with five taking place online and five in person. One of the project partners, Luciana Viegas of VNDI, was present at four of the interviews, with the interviewees' consent and acted as co-interviewer, asking follow-up questions and helping to introduce the project. The presence of the project partner was often useful as they gave feedback on the proposed research questions and suggested edits and additions for follow-

up questions, particularly around perceptions of autism, which aimed to reveal the approaches of service providers.

4.2.7. Data processing and analysis

Anonymity and data handling

Anonymity is an ethically complex subject, owing to the assumption that participants want or 'need' to remain anonymous for their protection. Obligatory anonymity has been challenged by qualitative researchers, particularly within Disability Studies, who have questioned this logic in line with emancipatory research principles as upholding paternalistic views of disabled people and their resultant exclusion from society (Graby, 2018). Complete anonymity also particularly poses challenges to co-produced research as it invisibilises contributions of participants or project partners to the study. However, identifying participants who divulged sensitive information during workshops that may place them at risk must be avoided. I decided, therefore, to take a careful approach to anonymity in consultation with the leading project partner, VNDI, and let them guide this process in consultation with local partners and network leaders. Therefore, some mothers' networks remained anonymous, owing to the sensitive nature of some of the topics discussed, such as domestic violence, and the worry that divulging the name of networks would put participants at risk. Names of networks where members did not participate in workshops or where it was agreed with local and leading partners that there was no risk to participants are included, in agreement with the mother-leaders interviewed (detailed in Table 4.1).

During the transcription phase, all identifying information from the data was removed, including names of participants and children, names of specific neighbourhoods and municipalities, schools, network affiliation or other information deemed to risk identifying participants. Pseudonyms or placeholders were used. Whilst direct quotes were included to give voice to the participants and improve the validity of the research findings (Guest, MacQueen, & Namey, 2012), paraphrasing to avoid direct quoting that would identify a participant and redacting parts of verbatim quotes ensured anonymity when discussing sample characteristics. This applies to data collected during conversation circles and via observations, interviews and all project outputs. I consider all personal information collected as part of this research to be privileged information, and it was managed as such, following GDPR guidelines as laid out in UK law.

Abductive thematic analysis

Social Science research is broadly defined as deductive, inductive or abductive, which describes how theory and research design are linked. Whereas a deductive research approach is informed by existing theory, inductive research generates new theory from empirical data (Bryman, 2012). An abductive approach sits somewhere in the middle and compromises between the influence of existing theory and theory generated via the empirical data collection (Thompson, 2022; Timmermans & Tavory, 2022). An abductive theoretical approach was chosen for this study, which aims to draw on existing theory to design the research and make new theoretical contributions by drawing on the empirical data collected. This approach informed the qualitative methodology chosen for the study. Timmermans and Tavory also suggest that taking an abductive research approach allows surprising themes to be generated from the research data (2022). Therefore, by taking an abductive approach, I was able to engage in a reflexive and critical engagement with the context in which the research took place, in addition to being guided by, and critical of, the existing literature.

An abductive thematic analysis was conducted, adapted from the 8-step guide to abductive thematic analysis suggested by Thompson (2022), which includes the following steps: 1. Transcription and familiarisation, 2. Coding, 3. Codebook, which elaborates on when to apply each code, 4. Development of themes, 5. Theorising, 6. Comparison of Datasets, or triangulation of data, 7. Data display and 8. Writing up. However, to introduce the participatory element to the analysis, I added additional steps after developing the initial themes and data presentation stages to get validation and feedback from the project partners and to check my interpretation of the dataset, as shown in Figure 4.4. The analysis cycle is not as linear as Thompson presents. Still, I found myself going back and forth between stages and returning to the literature throughout the process. For example, during the triangulation with existing data, writing and refining stages, I was still going back to adjust and interpret the codes and themes.

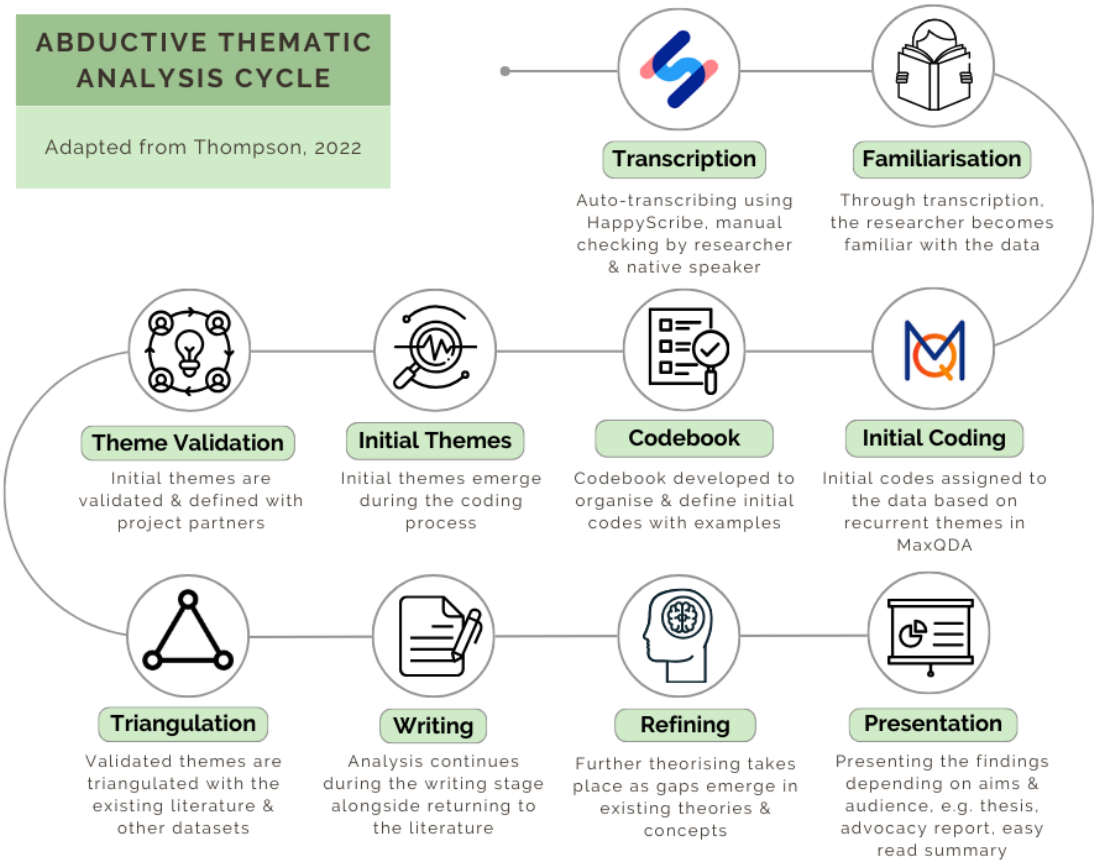


Fig. 4.4. Abductive thematic analysis cycle applied in this project, adapted from Thompson (2022)

MaxQDA was chosen as the analysis assistance software due to its usability and capability to streamline the analysis process via various tools. It must be remembered that analysis software cannot 'do' the analysis itself; it is a programme for managing, organising, and displaying concepts (Woolf & Silver, 2018). Since a large amount of textual data was collected from interviews, focus group transcripts and literature, MaxQDA was a helpful tool in managing this to make it more accessible for the analysis process. Since a variety of data was collected across various stakeholders, organising the data in MaxQDA allowed for easier comparison of themes across interview and focus group data and between research sites. For example, the theme of waiting lists for diagnosis occurred across all research sites. Still, interview and focus group data showed that waiting lists for an initial diagnosis were particularly long in the São Paulo research site.

Participatory analysis

An abductive thematic analysis was used to examine data from interviews, workshops, creative activities, and observations, with the method adapted to include validation by

project partners. This collaborative approach, described by Burns et al. (2021) as collective analysis, enriched the research by incorporating diverse perspectives, increasing data ownership, and enhancing potential for impact. Partner involvement—particularly from members of VNDI who were activists with disabilities and mothers of children with disabilities —strengthened the analysis, challenged my outsider perspective, and helped define key terms like *peripheria* [EN: periphery] to reflect participants' understandings. Partners also contributed to presenting the findings and co-producing outputs, including an advocacy report with an Easy Read[7] summary and social media graphics for wider dissemination (see Appendix J).

An additional element of checking my transcribing with a native speaker was also added to the transcription stage to improve accuracy. This multi-stage analysis is shown in Figure 4.4, and started with loose coding being applied during the transcription process and summaries of themes recorded from each interview or focus group transcript. Bryman advises that coding begin as early as possible to reduce the risk of being overwhelmed, increase familiarity with data, and assist with theoretical sampling (2012). The analysis was initially done in Portuguese, with codes being applied via annotations in the text, although summaries were written in English. I coded in Portuguese to facilitate the second stage of the analysis more easily with project partners, avoid having to translate all the data collected and avoid losing key themes and concepts that were difficult to translate into English. Once the transcriptions were complete, they were uploaded into MaxQDA to revise themes and codes.

4.3. Research ethics approval

Ethical approval for the project was submitted in both the UK and Brazil. I sought ethical approval from the University of York Economics, Law, Management, Politics and Sociology Ethics Committee (ELMPS) in the UK. Several revisions were made to the application before it was finally approved ahead of data collection in April 2023 through decision 44 22 23. In Brazil, I sought ethics approval via the national platform for ethical approval, Plataforma Brasil, through Instituição Instituto René Rachou/FIOCRUZ Minas, where my Brazilian supervisor was based. The project was granted ethical approval via Fiocruz (Certificate of Presentation of Ethical Appreciation number: 6964421.6.0000.5091) in September 2021 after one revision.

[7] Easy read is a way of presenting written information in an accessible format, using images and simple language to convey the information. It is designed to aid understanding of people with learning disabilities or others who struggle with literacy or processing text-based information.

4.4. Ethical considerations

Vulnerability

Vulnerability is contextual, subjective and applicable to all humans. According to Fineman, 'a vulnerability approach is not centred on specific individuals or groups or human and civil rights. It is not a substitute term for weakness or disadvantage, nor is it just another way to indicate impermissible discrimination' (2019, p.342). However, blanket labelling of certain groups as vulnerable can lead to their unnecessary exclusion from research, for example, people with learning disabilities. Therefore, a more nuanced approach is necessary to identify research participants' vulnerabilities, assessing them within the context of the research methodology. Participants included in this project may have some vulnerabilities owing to their previous experiences or identities, e.g. having a specific type of disability or health condition, having experienced trauma or abuse. Therefore, the participatory nature of the project aims to decrease vulnerabilities in the context of the project by challenging the historic power imbalances in researcher-participant relationships.

Sensitive topics

During research planning, the team and project partners discussed handling sensitive topics, such as domestic violence, by establishing clear protocols: reminding participants they were not obliged to disclose personal information, ensuring confidentiality, and allowing them to pause or withdraw at any time. We also planned referrals to local support services, including psychologists and counsellors. Concerns about managing sensitive disclosures were revisited during the research and evaluation stages, particularly regarding the emotional impact of open-ended questions, which at times led participants to share traumatic experiences. The team reflected on the ethical challenges this posed, including the risk of triggering others and the limits of our preparedness to respond appropriately.

Some researchers point to the risks of avoiding trauma research because it means that survivors' voices remain silent (Becker-Blease & Freyd, 2006; Bos, 2020). This was highlighted during the study, whereby during the workshops, two cases were identified where there was still potential risk of domestic violence towards women and one case where partners deemed a child was at risk owing to severe mental health issues and lack of support. The ability of participants to disclose these experiences during the workshops allowed the project partners and local partners to refer them to follow-up services and assistance that they might not have otherwise accessed, including psychologists, lawyers, and social services. Risks to participants were reduced through the anonymity of networks to reduce the risk of participant identification.

Risks to the researcher

Through the fieldwork design, I acknowledged that personal, psychological and physical safety risks could arise, as with travel to any location. Fieldwork was initially delayed owing to the COVID-19 pandemic, and I took precautions to mitigate the risk of COVID-19 to my safety and well-being. A risk assessment was completed before travel, and measures to reduce risks to the researcher were identified in line with the University of York's travel and research guidelines. Doing fieldwork alone in a different country carries a certain amount of psychological risk, which was partially mitigated through the participatory nature of the project and close contact with civil society partners throughout the data collection process. I remained in regular contact with my supervisors and friends and colleagues in the country and back in the UK. Whilst there were times throughout the data collection that were very stressful and exhausting, the long-term negative impacts of this were mitigated through peer and mentor support, rest and reflection.

4.5. Participatory evaluation of methods

The project incorporated participatory evaluation at multiple stages, aligning with Vaughn and Jacquez's (2020) definition of participatory evaluation as an approach that involves stakeholders in decision-making during the evaluation process. Although not part of a PhD process, participatory evaluation is more commonly included as an approach within many service-oriented sectors to improve organisational learning and practice (Rogers & Williams, 2006). The project team agreed that an evaluation was essential to support future funding, ensure accountability, and continue the project. Conducting the evaluation in a participatory way was key to including diverse insights and reducing power imbalances between participants, partners, and the researcher. As part of the project's commitment to reciprocity, the evaluation allowed partners to assess the impact of their involvement and understand how participants valued the intervention.

The evaluation took place in two phases: first, an anonymous Google form completed by workshop participants, and second, online meetings with project partners following data collection. The form collected quantitative and qualitative feedback on workshop logistics, research activities, and knowledge gained. Of forty-one workshop participants, 16 responded (40%), with the majority reporting high satisfaction and increased awareness of topics like ableism, racism, and disability rights. Participants most valued the conversation circles and information shared by project partners. Suggestions for improvement included more time for exchanges and better time management. The second evaluation phase, involving core team members and new participants from the partner organisation, added an external perspective to the evaluation process.

Reflections on conversation circles as a methodology

The conversation circle followed the access-mapping activity, allowing participants to elaborate on their experiences navigating health, education, and social service systems. The project team found this method particularly effective for generating rich data. Unlike traditional focus or discussion groups, conversation circles encouraged participant protagonism, enabling knowledge exchange and critical reflection on individual and collective experiences (Pinheiro, 2020).

Participants frequently interrupted for clarification, shared similar stories, offered advice and sympathy, and asked each other questions. In Bhia, participants demonstrated control over the process by managing the audio recording, moving the microphone closer to speakers and quieting others, reflecting a sense of ownership over the process. This may have been influenced by the group's larger size and shared network affiliation, which shaped both group dynamics and the power relationship between me, as an outsider researcher, and the participants.

Despite the risks of talking about sensitive topics in a group setting, there is evidence that there can be benefits to participants in getting the chance to speak about traumatic and isolating experiences in a safe, supportive environment and that the negative impacts of participating in research are often overestimated by researchers (R. D. Marshall et al., 2001). Indeed, there was some evidence from comments from the participants during the feedback form, who found the exchange during the conversation circle the most valuable aspect of the workshops. One participant commented,

> *'When we shared the stories, at that moment I realised how beneficial it was to everyone, even though we were talking about pain, there was an incredible welcome!'* – anonymous participant, Rio de Janeiro.

However, the conversation circle also had some drawbacks. The openness of the format and participant control occasionally led to the unexpected sharing of traumatic experiences, raising ethical concerns. These were later addressed through reflection and adjustments to the research design after the first two workshops. Some partners with disabilities found ableist views—such as the over-medicalisation of children—triggering, though those who were also mothers reported greater resilience due to their lived experience.

Additionally, audio quality during some conversation circles was poor, leading to data loss and increased time spent on transcription and translation. Despite these challenges, the method proved valuable, fostering authentic expression in a supportive group setting and offering insights not easily captured through traditional interviews or focus groups.

During the evaluation with project partners, we discussed strategies to mitigate the ethical issues around disclosure during future research, including better training and selection of team members and involving mental health professionals. However, it was also noted that including healthcare professionals could alter the dynamics, prevent participants from opening up and risk medicalising the space. Whilst including people with disabilities as part of the research team enhanced the research and impact, better mental health support is needed in future projects. One solution suggested was having mothers of children with disabilities who were also people with disabilities themselves to facilitate workshops, since they brought a unique and sensitive perspective to the research, informed by their lived experiences.

Reflections on interviews

Generally, interviewees were open and interested in the project and happy to give their opinions freely or make suggestions on where else to get information. The interview questions were formulated around the research questions, aiming to gather information to answer each question (see Appendix H for interview questions guide). The target groups were chosen with the project partners, depending on which group we thought would have the most relevant knowledge.

4.6. Chapter summary

This chapter has explored the research design and evaluation methodology through participatory methods with civil society project partners as community representatives. I have attempted to be transparent about the realities of doing 'messy' participatory research and the ethical implications of power imbalances that cannot be neatly resolved through partnerships, but perhaps lessened through uncomfortable reflexivity (Pillow, 2003), development of a common language (Tiffany, 2006) and critical engagement with the context of the research. The guidance of the project partners in the development of the research questions, methodologies, choosing research sites and assisting in the organisation of workshops was a key element in the participatory approach to the study that aligns with a CDS methodology, in line with the principle of 'nothing about us, without us' (Charlton, 2000).

The chapter also laid out the mixed methods employed in the research, blending traditional qualitative methods with creative and culturally appropriate conversation practices, which resulted in rich qualitative and visual data. Visual and innovative methods were utilised to encourage a more horizontal dynamic between me as the researcher, the project partners and the participants, and to more easily facilitate discussions to answer the research questions rather than a data collection tool (Lewin & Shaw, 2022). Data from conversation

circles was supplemented with interview data with professionals and mother leaders. Finally, an abductive thematic analysis cycle was applied, adapted from Thompson's guide (2022) to include the participatory elements involving the project partners. In the following three empirical chapters, I will present the data and key themes that arose through the analysis process, starting with analysing the experiences of mothers of children with disabilities in the peripheries as 'shrunken affordances'.

Chapter 5 - The periphery as a context of shrunken affordances

5.1. Introduction

The previous chapter outlined the research design, ethics, evaluation approaches, and study limitations. Rich qualitative data were generated through interviews and workshops using creative methods and conversation circles that encouraged mothers to share their stories openly. The abductive analysis draws on the theoretical framework introduced in Chapter Two—Kafer's (2013) political/relational model of disability—through an intersectional feminist lens that extends Dokumaci's concepts of microactivist affordances (2019) and people as affordances (2020) to examine mothers' experiences and actions in the periphery. This is blended with theory emerging from empirical data in Chapters Five, Six, and Seven to develop a theory of *shrunken affordances*. Adapted from Dokumaci's (2019) "shrinking affordances," I use the adjective form to emphasise a *state of being* shaped by chronic denials of access within the periphery, produced by intersecting systems of oppression. This theory emerges through a continuous dialogue between theory and data.

This first empirical chapter introduces key themes from the data, focusing on how disability narratives, information, and access to services shape the experiences of mothers of children with disabilities in peripheral areas. The first section addresses the sub-question: *What types of disability narratives and information do mothers have access to in peripheral areas?* It centres on the diagnostic process, which often served as the starting point of mothers' stories and as a gateway into their experiences. I then analyse how dominant disability narratives influence mothers' responses to diagnosis, followed by the role of post-diagnostic care and the information provided.

The second section examines mothers' access to state support, specifically social, educational, and health services, as shaped by the availability and quality of information and service provision in peripheral areas. However, mothers' speeches were largely focussed on health and social care access, with less focus on education, although it did appear as a key issue. This section addresses the sub-question: *How are mothers' experiences shaped by state support and services in peripheral areas?* Five key themes are explored: provision and affordability; denial and precarity; private healthcare access; and lack of time. Data is presented through direct quotes to centre mothers' voices, alongside abductive thematic analysis triangulated with existing research and policy.

In these chapters, I use 'participants' to refer to the group generally, and the terms 'mothers', 'mother-leaders', or specific professional roles when referring to individuals. Ten

interviews were conducted with professionals, including social workers, psychologists, a municipal manager, and mother-leaders. Eight conversation circles were held with a total of 41 participants, though verbatim quotes from only 26 mothers are included in the empirical chapters. To protect identities, names have been replaced with numbers indicating the conversation circle, order of speech, and location (e.g., *mother 6.1, São Paulo* refers to the first speaker in circle 6, held in São Paulo). A few quotes from creative writing exercises are cited as 'anonymous mother, [location]' when the speaker could not be identified. Seventy-seven people completed an online survey prior to the workshops and circles; this data informs the statistical findings, though the survey was anonymous and not all respondents participated further.

5.2. Navigating diagnosis and medicalised disability narratives

I present here my argument that the dominant disability narratives and information – meaning, firstly, the ways in which disability is approached and dealt with through systems, and secondly, disability discourses used by professionals, parents, and wider society - impact on the experiences of mothers and their children in accessing state support and services. Through mothers' diagnosis stories and reflections of professionals, I explore the medicalisation of disability and childhood by the system, professionals and parents. I suggest that medicalisation is supported through the dominance of biomedical narratives, which emphasise the underlying biological and impairment aspects of disability and are tied to a deficit model (Forstner, 2022), and the lack of post-diagnostic support, including information about rights and services. I further suggest links between the types of information and support mothers receive and the ways they deal with diagnoses.

5.2.1. Diagnosis as a doorway – 'It's really bad, when you don't have a diagnosis and no one pays attention'

The diagnosis doorway

Children's diagnostic processes were central to mothers' accounts of accessing support services. In Brazil, a diagnosis and *laudo médico* [EN: Medical Disability Report] are often prerequisites for accessing disability-related services and benefits, making diagnosis a critical gateway to rights and support. This reflects a biomedical, binary view of disability, where legitimacy as 'disabled'—and thus eligibility for services—depends on alignment with medical classifications (Kafer, 2013) like the ICD-11. Without a formal diagnosis, access to healthcare, therapies, medication, benefits, and assistive devices is often blocked. A 2021 Brazilian government report acknowledged this binary, biomedical model as limiting, noting it hinders public policy focus and excludes many with significant participation restrictions

(Ministério da Mulher, da Família e dos Direitos Humanos; Secretaria Nacional dos Direitos das Pessoas com Deficiência, 2021, p. 33). In response, public consultations have been initiated to develop a unified evaluation model based on a biopsychosocial understanding of disability. However, as this model is not yet implemented, my analysis focuses on the current biomedical diagnostic system and its effects.

Undiagnosis, time and shuttling

Almost one quarter of those who filled out the online survey said that their child had been denied a Medical Disability Diagnosis at some point. Although most families had eventually been successful in obtaining a diagnosis for their children, mothers talked about the diagnostic processes in terms of temporality: the process was often slow and bureaucratic and created delays in access to other services and benefits. Under the wider umbrella of Crip Time, Kafer (2013, p. 37) refers to this 'the time of undiagnosis', which includes activities related to the diagnostic process, including, 'the shuttling between specialists, the repeated refusal of care and services, the constant denial of one's' experiences, the slow exacerbation of one's symptoms, the years without recognition or diagnosis, the waiting'. This resonates with the experiences reported by mothers in this study and the impacts on the time they spent pursuing a diagnosis as the first step to getting access to other support, such as extra support at school, therapies, social assistance, disability benefits or assistive devices.

Helena Fietz (2023) applies an interpretation of Crip Time in the analysis of the time of mothers of adults with intellectual disabilities in Brazil. In doing so, she identifies a key element of crip/care time as the time spent on '*luta*' [EN: struggle] activities and waiting to access services, which pushes back against linear 'productive' time that is considered the norm. These experiences also reflected those that the mothers described during the conversation circles, many of whom also described their experiences using the term 'luta'. We can therefore consider the 'time of undiagnosis' as the time spent on this struggle. An understanding marks a pivotal doorway into the world of disability information and support services, and, in turn, into micro-activist performances, which I will expand on in the following chapter.

Chapter Three (section 4.2) explains that the medical disability report uses the ICD coding system. Since some public healthcare centres specialise in certain classifications and this information is not readily available, mothers could experience Kafkaesque scenarios - being sent from one centre to another to find healthcare professionals qualified to deal with their child's specific ICD. High levels of bureaucracy typified mothers' experiences throughout the 'time of undiagnosis' (Kafer, 2013, p. 37). Indeed, mother leader 1, Rio de Janeiro, used the same 'shuttle' analogy to explain why, in the favela where the network operates, *most autistic people are not diagnosed… Because they keep making the mother a shuttlecock.'*

Here, she is specifically referring to the experience that mothers have of being 'shuttled' back and forth between healthcare centres or healthcare professionals during the process of diagnosis and obtaining a medical disability report [PT: *Laudo Médico para PCD*], which added considerable time and stress to the diagnostic experience. Mother 5.4, who was part of the same network, reflected on her own '*tiring journey with SUS'* during the conversation circle, explaining, *'maybe a neurologist is far away…sometimes the neurologist doesn't comply with the ICD of the person in question.'* This had been the case with her own son, and so she had been *'to three different neurologists who didn't comply with the [Autism] ICD.'* Furthermore, a lack of clarity on who has the authority to 'close' a diagnosis means '*you're like a ball between the neurologist and the psychiatrist'.*

Similarly, in São Paulo, 'crip time' was added to because of the lack of public healthcare centres qualified to provide Autism diagnosis. The social worker at an APAE[8] centre noted that although technically the Child and Adolescent Psychosocial Care Centers [*PT: Centro de Atenção Psicossocial Infanto-Juvenil (CAPSi)*] are designated to process disability diagnoses and provide medical disability reports via the SUS, in the case of Autism diagnosis they were not always equipped to do so *'because to make a diagnosis…clinically, of autism, there are specific tests, right? …And they don't apply them.'* Additionally, mothers' experiences illustrated how, despite the right to access healthcare, including early diagnosis and intervention via the SUS being guaranteed by the Brazilian Law of Inclusion (BRASIL, 2015), this was not always guaranteed owing to a lack of qualified staff, unclear assessment and diagnostic processes and long wait times. We can see here how the inadequacies of the diagnostic system design and lack of information impacted the time spent on shuttling, rejection, and waiting, and the resulting mental distress, forming part of the 'time of undiagnosis' (2013, p. 37), which characterised the experiences of mothers.

Mental health impacts

This shuttling and rejection mentioned in the previous section had a negative impact on mothers' mental health as it generated stress and exhaustion. Mother-leader 1 in Bahia described how healthcare professionals '*kept sending me to a different place. So I had a crisis in the middle of the street, because I spent 40 minutes walking from one place to another; "oh, it's not here", "Go to* I-don't-know-where *to look for it"'.* We can also view

[8] APAE stands for Associação de Pais e Amigos dos Excepcionais [EN: Association of Parents and Friends of the Exceptional]. According to the APAE Brasil website, 'the National Federation of APAEs, or APAE Brasil, is a non-profit social organization, recognized as a federal public utility and certified as a charitable organization for social assistance, of a cultural, welfare and educational nature, which currently brings together as affiliates more than 2,200 APAEs and affiliated entities and 26 State Federations, which make up the APAE movement, with the institutional mission of promoting and articulating actions to defend the rights of people with disabilities and representing the movement before national and international organizations, to improve the quality of services provided by APAEs, with a view to the social inclusion of their users' (2025).

these acts of 'struggling' for a diagnosis and access to services as part of Blum's accountability to a 'standard of relentless action' (2007, p. 21). As such, mothers who do not pursue a diagnosis and treatment for their child would be and are judged as 'bad mothers'. Douglas (2016) points out that this regulation of motherhood is necessary as part of the governance and production of an idealised human 'norm' which is upheld by Western science-backed neoliberal capitalism. We can therefore see these activities to which mothers are subjected - identifying 'the problem' and pursuing a normalising process of therapies, treatments and diagnosis - as part of the regulation and classification of disabilities against the idealised norm through the diagnosis process.

Waiting Lists

Being placed on a waiting list emerges as another key element of the time of undiagnosis, which can extend beyond the point of diagnosis. For example, when a specialist service - usually medical or therapeutic - is located, families must wait indefinitely for appointments, medical exams, or a 'place' for their child to receive treatment or therapy. The topic of waiting lists came up 31 times in total and consistently across all research sites as a key barrier or delay to accessing all types of healthcare, from medical consultations to therapies and testing. However, participants across all research sites noted that the longest waiting lists for an appointment were for an initial appointment with a neuro pediatric doctor after referral from a primary health unit [*PT: Unidade Básica da Saúde (UBS)],* the gateway to the SUS. For example, the municipal manager in São Paulo noted that waiting lists could extend *'three months, six months, a year and even cases that were for years.'* From mother 5.1.'s perspective in Rio de Janeiro, this impacted many mothers she knew who *'struggle a lot…I know many mothers who have children who are still on the waiting list for neurology, for years. For speech therapy, for…literally years.'* An initial appointment with a neuro pediatric doctor was usually just the starting point for the diagnostic process, which was further extended by waiting lists for testing or treatment, indicating that the 'time of undiagnosis' (Kafer, 2013) could last much longer than this. The extension of this waiting period directly impacted the experiences of mothers and their children, who could be left in limbo without access to other services until diagnoses were complete, only then to join other waiting lists for healthcare services.

Diagnostic legitimacy

As already mentioned, medical diagnosis provides a stamp of authority by classifying a disability against the ICD, which denotes the type and location of healthcare they can access. I suggest here that this is a key feature of the binary, biomedical approach to disability that dominates the Brazilian healthcare, education and social assistance sectors. As a mother in São Paulo explained, '*today I have [the diagnosis], but before I didn't. Every time I had to talk about everything. It's really awful when you don't have a diagnosis and no*

one pays attention.' She further elaborated how '*if we had this diagnosis at the beginning, it would change [daughter's] life a lot.'* She had subsequently spent the first few years of her daughter's life chasing a diagnosis for her rare disease, which had barred access to therapies, accurate healthcare advice and treatments.

The case of Congenital Zika Syndrome (CZS) illustrates how difficulties in diagnosing rare or emerging conditions can leave children indefinitely in what Kafer (2013) calls 'the time of undiagnosis'. As Mother Leader 2 in Bahia explained, '*since there was no test to prove it, we saw people without a diagnosis, but …they were children who could have had Zika, especially because Zika was asymptomatic.*' Many children with CZS became entangled in slow, bureaucratic processes—particularly when symptoms didn't align with ICD criteria. For instance, those without microcephaly, a 'typical' CZS feature, were often misdiagnosed or undiagnosed, excluding them from vital services and benefits (Bachtold, 2019; Lowe et al., 2018). This lack of diagnostic legitimacy reinforces the ideal of the 'good' mother-warrior (Douglas, 2016), where securing a diagnosis is tied to maternal responsibility and the governance of normality. Diagnosis, then, becomes a tool for both pathologising difference and accessing rights. While problematic, medical diagnosis remains crucial for securing healthcare—access to which is often shaped by geographic, socioeconomic, and racial disparities.

Geographic, socioeconomic and racial disparities

Access to healthcare services in Brazil is profoundly marked by racial, socioeconomic, and geographic disparities, with Black, peripheral communities most likely to experience barriers to medical diagnosis. For example, the Black population has less access to specialist healthcare (Tomasiello, Bazzo, Parga, Servo, & Pereira, 2021), and the north and northeast regions with the highest Black populations and lowest socioeconomic indicators experience the greatest healthcare access disparity (Coube, Nikoloski, Mrejen, & Mossialos, 2023). Whilst mothers did not explicitly link delays in diagnosis to racism during the conversation circles, the online survey data revealed a racial discrepancy, with 27% of Black children experiencing delays to diagnosis in comparison to 10% of white children.

The project partners, VNDI, confirmed that obtaining a medical disability report is a recurring challenge of Black communities, especially in the northeast, and forms part of their ongoing advocacy work. Their claim aligns with research showing that although the Health Care Law (Law 8080/90) improved health equity for Brazilians overall, SUS reform since 2016 has led to defunding of the service, widening of geographical inequalities and worsening of health indicators, especially for the poorest children in the Northeast of the country (Ortega & Pele, 2023). This indicates that socioeconomic and geographical disparities have a disproportionate impact on Black children with disabilities and children with disabilities in certain locations. Whilst this study cannot make definitive comparisons,

families in Bahia likely faced greater barriers, to be discussed in the following half of the chapter.

5.2.2. Medicalisation of disability and its implications – *'We forget about the human aspect.'*

Although biomedical approaches to disability were not the only disability narratives identified, they arose as a dominant theme in the data collected across all sites. This observation was consistent with previous research and observations by the research partners that the biomedical approach still dominates services for people with disabilities in Brazil (Bampi, Guilhem, & Alves, 2010; Panisson, Gesser, & de Andrade Gomes, 2018) and that Black, peripheral, poor children with disabilities are subject to even more segregation and disadvantage (M. C. N. Moreira, 2022), especially concerning access to healthcare (Ortega & Pele, 2023). I suggest here that the dominance of the biomedical, binary model designates how children with disabilities are seen and dealt with across services and broader society, including within their own families, and that this significantly impacts the experiences of families in peripheral areas. The dominance of the biomedical and binary framings of disability also impacted and was exacerbated by the lack of provision of information and alternative disability narratives that took a holistic and rights-based approach within peripheral areas. Medicalisation of disability is therefore to be presented in three main ways through the data collected: disability narratives and information provided to mothers, use of medication and attitudes of parents.

Biomedical disability narratives and their impact

While some mothers encountered supportive professionals, others described ableist attitudes that reduced their children's lives to medicalised notions of abnormality or tragedy. In a Rio de Janeiro conversation circle, one mother recalled giving birth six months prematurely to a daughter who died shortly after, '*the only thing the doctor said was, 'look, if she survives, she will need a lot of things, she will not be normal*.' Similarly, Mother Leader 1 in Bahia shared how mothers in her network received 'absurd', limiting prognosis after Autism diagnosis. Such comments reflect the dominance of a biomedical model of disability in Brazil's healthcare (Ferst & Cunha, 2025; Ministério da Mulher da Família e dos Direitos Humanos, 2021) and social assistance systems (Panisson et al., 2018). While professionals may intend to prepare mothers for the realities of disability, these negative framings can be harmful. Research on caregivers of children with CZS found that such narratives negatively affected mental health, motivation, and trust in professionals (Simas et al., 2020). These findings point to the need for improvements in health and social care, and broader challenges tied to the medicalisation of disability and childhood.

Since disability diagnosis happens mainly in healthcare settings, mothers often receive only medical reports and therapy guides. This unintentionally reinforces a dominant medical view of disability, as it is not complemented by rights-based information. In some cases, mothers were left without information to fully understand the implications of the diagnosis of their child, only receiving the medical name for the disorder on the medical report, which could also be inaccessible. In the experience of mother leader 1 in Bahia, on receiving her son's medical report, which read *'Pervasive Developmental Disorder',* she *'didn't know what that was, at the time.'* Yet, beyond a list of places where she could take him for therapy, she had received no other information at the point of diagnosis. Whilst it is not to critique the sharing of this information *per se*, I mean to highlight here how dealing with disability diagnosis exclusively within a healthcare setting systematically limits the information provided to medicalised disability narratives.

The dominance of the biomedical approach and focus on treatment and therapy was recognised to a certain extent by the social worker interviewed in São Paulo. She described how the APAE centre where she worked had allowed a young Autistic boy to undergo intensive early intervention therapies (therapy type was not specified) at the insistence of his father until, eventually, '*the boy got sick*'. She admitted that *'we also make a lot of mistakes…it's rare that we see the human aspect. We forget about the human aspect of people.'* Although she did not elaborate about why the organisation had allowed a child to undergo therapy that made him sick, her comments about the approach of APAE provide some illumination. *'I think it varies a lot from APAE to APAE…we have to understand that it's the family but there's still more focus on therapy, it's the therapy, it's the care, it's the child.'* I propose here that, despite variation across services, even within the same network (for instance APAE), biomedical framing of disability remains the default in healthcare and social care. This framing is reinforced by a lack of alternative information, such as social, human rights, and biopsychosocial perspectives, on rights, laws, and non-medical services, especially at the point of diagnosis or discovery.

Medication

Many mothers reflected on their experiences with diagnosis and healthcare access, expressing concern about overmedication, particularly for children diagnosed with Autism, ADHD, and other psychosocial disabilities like schizophrenia, which are often treated primarily with medication. In some, but not all, cases, medication was the only treatment offered, especially where waiting lists for other therapeutic treatments were long. In Bahia, mother 2.4 described an instance whereby age-inappropriate medication was prescribed for her Black son by a doctor, resulting in serious health implications. '*Dr [name] gave… Neuleptil [antipsychotic drug] that my son, guys,* he couldn't walk [mother's emphasis]'. When she questioned the prescription after noticing negative side effects, the social worker had *'said to my face that I wanted to be more than the doctor, she wanted me to continue*

giving Neuleptil to kill my son.' Eventually, she discovered through a toxicology report that the doctor did not follow the medication's age restriction, leading to serious implications; '*the exam said: the Neuleptil – guys - it almost killed him. Do you know why? He took very strong Neuleptil when he was four years old. Now he can take it, he's 12, but it wasn't possible to take Neuleptil when he was four years old.'* Whilst this was the only incident reported by a mother whereby a doctor prescribed age-inappropriate medication, other mothers described situations indicating how medication was indiscriminately prescribed for children based on their diagnosis.

For example, mother 7.2 in São Paulo described how her young, Black son had been prescribed medication automatically after receiving his Autism diagnosis without further investigation or examination.

> *'[My son] was diagnosed when he was three, three and a half years old…one of the first things that happened was during our appointment with the psychiatrist, she linked autism to medication. Without knowing, without having done any kind of examination, without having any kind of perceptiveness about him.'*

The reports from mothers indicate that indiscriminate prescription leading to overmedication or inaccurate medication is a risk for children. The research partners also noted that indiscriminate prescription, including over-medication of Black children, particularly boys, as demonstrated in the two cases presented, is common. Although there is a lack of research on the topic, many Black Autistic activists in Brazil also note the simultaneous overmedication and difficulty in getting a diagnosis or misdiagnosis with mental health conditions, particularly for Autistic people labelled as 'high functioning' (Morosini, 2023; Viegas, 2020). Furthermore, research indicates that there may be over-prescription of Ritalin for children and adolescents in the country (Itaborahy & Ortega, 2013), which saw a 775% increase in prescriptions for children and adolescents with ADHD between 2004 and 2014, bringing it to second place for national Ritalin use worldwide (Agência Câmara de Notícias, 2014).

Whilst there have been attempts to regulate overmedication through legislation since this data was made public, more recently experts have warned that continuing high rates of indiscriminate use of Ritalin for children who are Autistic or have ADHD in the country are linked to the 'Autism epidemic' that is a result of vague diagnostic criteria (Agência Senado, 2023). Moysés and Collares further link to medicalisation and pathologisation of difference in order to control and subdue children instead of addressing the serious inadequacies of the education system, which they argue contributes to racist stereotyping of Brazilians and Black Brazilians in particular as inferior (2013). I reflect here that whilst overmedication is tied to the medicalisation of children and the education system and the pathologisation of disability, it is also a result of the same system that creates barriers to access to quality healthcare, which also prevents access to medication, especially for peripheral

communities. It is therefore important to study these nuances to avoid making overarching statements about overmedication when, in fact, access to medication is also an issue that I will further explore in the second half of this chapter.

Although the medication of children was, at times, questioned by different mothers during the conversation circles, as above, at other times it remained unquestioned or reinforced. At the end of the training where the project partners had discussed social approaches to disability, one mother reflected that, *'when you receive your [child's medical] report, it was like, "Wow, she's going to have to use medication because of the autistic report" … it's automatic, right? You're already going to think about pharmacy, medicine that is therapeutic care, right?'* She further reflected that until she had heard about disability and Autism presented in non-biomedical framings during the partner training, she *'didn't stop to think like that, what about it being also being social?'* This mother was not part of a mothers' network and had limited contact with other mothers who had children with disabilities. It is possible that her assumptions about the need for medication for some diagnoses were less likely to remain unchallenged by alternative non-biomedical narratives to disability and neurodiversity because of her lack of contact with a mothers' network, where such narratives might be circulated. This will be explored further in the following chapter.

5.2.3. Dealing with a diagnosis - *'when you're going to have a child, you idealise it, you dream about what your child is like'*

The process of dealing with the discovery of the disability or diagnosis of a child was central to the experiences of mothers and was a key part of mothers' speeches, many of whom spoke about it as a difficult process of adaptation away from their imagined futures and former realities. The difficulties that parents have in accepting their child's disability and diagnosis underscores a key issue contributing to the contested space of parents in disability activism, as outlined by researchers in other contexts (Carey, Block, & Scotch, 2020; Morrison, Woodbury, Johnston, & Longhurst, 2022), hence why it is important to understand this process and where it sits in relation to mothers' experiences, including their drive to activism, as will be explored further in the following chapter. In this section, I turn my attention to the way in which the diagnosis or discovery of disability impacted mothers, particularly in relation to their mental health and how this was related to the support that was available to them.

Da Paz et al. (2018) call this process 'maternal adjustment', which is characterised by three dimensions - acceptance, self-blame and despair. According to their study, acceptance is associated with better mental health over time, and self-blame and despair with worse

mental health and life satisfaction. Rapp and Ginsburg talk about this struggle with acceptance slightly differently, framing it as an episodic rather than a linear journey that does not always end with acceptance or readjustment that 'incorporate[s] their child's difference into a comprehensible narrative' (2011, p. 392). Seeing this process as episodic and continuous rather than linear towards an end goal helps to highlight some of the tensions in presenting mothers as activists, especially since full acceptance is not always achieved. I also highlight here that acceptance of a disability or diagnosis is different to acceptance of the difficult situations that mothers and their children find themselves in, which can be a catalyst for activism. As Crow and Merchant (2019) note, as disabled activist mothers of disabled children, they occupy a difficult space between the parents and disability movements, yet also recognise their own difficult feelings related to their children's impairments and futures. These difficult feelings of mothers were often entwined with each other and with the feelings and opinions of those around them. I acknowledge this complexity but present them separately to analyse five themes: idealisation, grief, denial and cure seeking, blame and rejection and acceptance.

Idealization

We can understand these initial feelings of mourning and loss as linked to a parent's idealisation of the 'perfect' child before they are born, which then sharply contrasts with the reality of a child with a disability who they, or society, see as abnormal, imperfect, or unhealthy. As another mother 2.3 in Bahia put it, '*when I got the diagnosis, I suffered a lot, because no one expects to have a child with a disability, any limitations. She hopes to have a healthy child.'* Similarly, mother leader 4 in Rio de Janeiro, explained how at first, she had also struggled to accept her son's disability, after he was born with cerebral palsy following complications with his birth; '*First I cursed, I fought with God. And then I fought with the doctors' telling them*, '*"I didn't ask for a sick child!*"' In this case, the acceptance of her son's disability and diagnosis was also tied to her own traumatic experiences giving birth, where she described how the doctors had initially refused to give her a caesarean section because she was a Black woman. '*What caused my son's disability was perinatal anoxia due to a medical error*.' In her words, '*I gave birth to a perfect child, they gave me a child with a disability*'.

This contrast between the imagined child and future and the reality can therefore lead to mental anguish and even denial, as the parent tries to resolve this difference and adjust expectations. In the case of some mothers, including mother 2.3 Bahia, they had '*denied for a few years that this is what [son] had, this disability'.* However, during the data collection and discussions, the project team recognised that most mothers had largely been exposed to negative, biomedical and tragedy models, which impacted their reactions. Although challenging to draw definitive conclusions about the links, research suggests that how and when children are diagnosed can impact parents' reactions, including acceptance and

readjustment (Kisler, 2014). It is also possible that dominant societal framings of disability influence mothers to internalise societal pressure to produce 'perfect' children, which Frederick (2017) refers to as part of the neoliberal 'normalcy project', which impacts their reactions to disability discovery.

Grief

Mothers' narratives revealed an episodic process of adjustment, in terms of expectations and acceptance of their child's disability, sometimes typified by feelings of grief, loss or mourning on discovery of a child's disability, akin to findings of previous research (Bravo-Benítez, Pérez-Marfil, Román-Alegre, & Cruz-Quintana, 2019; Fernández-Ávalos, Pérez-Marfil, Ferrer-Cascales, Cruz-Quintana, & Fernández-Alcántara, 2021; Green, Darling, & Wilbers, 2013). Mother 7.1 in São Paulo described going through multiple phases after her daughter's birth, reflecting the contrast between her imagined future: *'you idealise it…you dream about a future for them…when you come across such a reality, it comes as a shock to you.'* The initial shock and following state of mourning she describes can be interpreted as a 'loss' of the imagined child, leading to what Da Paz et al.(2018) call despair. For mother 7.1, a state where she experienced *'a state of mourning…I cried every day…isolated myself... I couldn't accept dealing with what was happening.'* Fietz (2023) further points out that this reaction is exacerbated by the distance of mothers from social movements of people with disabilities and lack of exposure to ideas of disability as a social and political category, although this changes through time as they adjust their expectations. I propose that connection with other mothers can similarly support emotional adjustment, which will be further explored in the following chapter.

Denial and cure-seeking

Initial denial of diagnosis and disability was reported both by mothers themselves and by professionals during interviews and was, at times, linked to the pursuit of a cure. The social worker at the APAE centre in São Paulo described how parents of children diagnosed as Autistic sometimes appeared to seek a cure, hoping that with enough therapy, children would '*get better*'. She also linked this type of cure-seeking to a denial or downplaying of the diagnosis, where parents *'say 'it's not a lot of autism…it's autism, but it's not that much, it's not a lot.'* On learning of an Autistic diagnosis, she described how parents sought information online to confirm their beliefs that a child could become *'normal'* with therapy and treatment. This belief could also influence parents' demands for therapy, as was demonstrated in her story about the intensive therapy that made an Autistic boy sick, presented in the previous section. She elaborated how some parents demanded high frequencies of therapy for their child, talking from *'this perspective that [therapies] will heal [Autism].'* That said, it is not clear to what extent this medicalisation and focus on cure was influenced by the APAE centre's approach, from the parents themselves, from the internet

where they sought information or from wider biomedical understandings that are hegemonic in Brazilian systems and society in general, as previously outlined.

Mother-blame and rejection

Mother-blame, which Linda Blum (2007, p.202) defines as fear of 'being judged inadequate, unnatural, or selfish', was a common feature in the experiences of many mothers. Participants discussed this blame as being externally influenced by fathers, families and wider society, and internally, linked to guilt. The psychologist working in the SUS observed '*the mother saying "ah, but it's my fault" The child was born like this…If I generated it, I automatically take the blame.'* It is possible that for some, this self-blame was linked to their difficulties in accepting a child's disability and the grief that could be connected to this.

It is not clear to what extent internalised blame was linked to externalised blame from others. For example, mother leader 1 in Bahia explained her own and other mothers' experiences of being blamed by others for 'producing' an Autistic child and held responsible for their behaviours. She described how in the initial period after receiving her son's Autism diagnosis, she '*heard that phrase "your son is autistic and it's your fault" a lot'.* She also noted that blame from fathers was common, saying *'a sister of an autistic teenager, she turned around and said to me: "My father, to this day, still blames my mother for my sister's autism."* Blame appeared to be closely related to rejection, with several mothers describing how their children's fathers had not accepted the diagnosis of their child, or rejected that the child was theirs after a diagnosis. Mother 5.1 in Rio de Janeiro said, '*I'm also alone because at the time his father rejected him, right? Saying there was something wrong, the child wasn't his.'* This blame has been linked in previous studies of fathers' inability to accept a 'non-perfect' child and the high rates of fathers abandoning mothers of children with disabilities and rare diseases in Brazil (Albuquerque et al., 2019; Ministério Público do Pernambuco, 2015).

Other mothers also noted feeling rejected by wider family and community. For example, mother leader 1 in Bahia related how she felt that she was judged for her son's behaviour at a birthday party. Similarly, mother 7.1 in São Paulo related how she '*avoid[s] going to family parties*' because they ask a lot of questions '*as if it were a monster, right? Like my daughter was, "wow, it's an alien*". Whilst the focus of this study was on mothers, recognising them as the primary caregivers of children with disabilities, the rejection of fathers in particular, but also the rejection of the wider family and community, stands out as an important factor influencing mothers' and children's experiences. I highlight this as a key issue for further research.

Acceptance

Many mothers who took part in the research appeared to have reached a level of acceptance of their child's disability or diagnosis after having gone through a process of adjustment, which varied significantly between mothers. Mother 2.3 in Bahia, who had denied her son's Autism diagnosis for the first few years, explained how her perspective had eventually changed; '*Today I say that I accept that my son has a disability…I am proud of my son...I go to the places where I can be with him, I don't go to the places where I can't. I don't get sad*.' Similarly, mother leader 3 in Bahia described through her process of adjustment how *'[son] didn't enter my world. I had to enter [son]'s world. I came to know him'.* She further described how her lack of knowledge had impacted this process of adjustment and on her acceptance of him, *'I knew he had autism, a disability, but I didn't have the knowledge that deep down it meant all that, and I suffered until I sought this help.'* The role of support and knowledge about children and their diagnoses or disability appeared to be important in how mothers adjusted after the period of disability discovery, expanded in the following section. Nonetheless, even having passed through the initial denial and grief stages and 'accepted' their child's disability or diagnosis, mothers might still hold ableist and negative views of disability, and grapple with feelings of loss and grief that were complicated by the systemic oppression that they and their children faced in daily life. Post-diagnostic care and support were also crucial in how mothers dealt with the diagnosis.

5.2.4. Post-diagnostic care and support - *'we are deficient in information'*

Green et al. (2013) identified a common theme in the literature of parent experience to be that of *anomie*, which they define as feelings of powerlessness and emotional stress in response to a lack of information and professional support following disability discovery or diagnosis. The importance of post-diagnostic care and support, including service support that is not medically oriented, has therefore been identified as a key factor influencing the well-being and quality of life indicators of parents and their children (Da Costa et al., 2023; Duttine et al., 2020; Shilling et al., 2013). It has been seen as especially important to help parents deal with post-diagnostic feelings of grief (Bravo-Benítez et al., 2019). As noted in the previous section, medical information provided to mothers on the diagnosis of their child could also be inaccessible due to medical disability jargon. For mother 5.1 in Rio de Janeiro, she saw her child's Autism diagnosis as being '*parachuted into this world of disability'.* For mothers without any previous knowledge or experience of specialist systems before the arrival of their child, the absence of this essential knowledge was keenly felt. Two sub-themes broadly characterised lack of post-diagnostic care and support, rights-based information, and emotional support.

Lack of rights-based information

The lack of information provided to mothers about the rights-based approach of Brazilian law and related provisions, including social assistance policies and benefits, inclusive education policies and legislative processes to protect against discrimination, was pervasive, with negative impacts. In relation to signposting during the post-diagnosis phase, it was reported by both mothers and professionals that '*[mothers] don't receive… this information when they receive a diagnosis'* [mother leader 1, Bahia]. According to the SUS psychologist, lack of knowledge impacts mothers' mental health, observing that '*they arrive very fragile, very vulnerable… given the lack of knowledge, sometimes they don't even know where to start.*' We can observe this as anomie linked to the lack of information provided by professionals (Green et al., 2013), especially after disability discovery.

The SUS psychologist further gave the example that most parents were unaware of the right to inclusive education and processes to appeal against denial of school places under the Brazilian Law of Inclusion (BRASIL, 2015), which created vulnerability to discrimination. In her experience, *'many mothers… they don't know that they have the right to appeal…So, mothers leave it at that because they don't have knowledge about it.'* The private sector psychologist further pointed out that service professionals were left without knowledge of rights and policies. During a training course she delivered to other professionals, she was shocked to find '*teachers who have been on the journey for a long time and have never heard about rights. It's the law!'* We can see here how a lack of knowledge of the rights-based focus of Brazilian law is part of a wider systemic issue that leads to further exploitation of parents and children, who are left ignorant about their rights to protection from discrimination.

It was inconclusive whether social class and private or public service use made a difference to parents' knowledge. Both of the psychologists interviewed indicated that the lack of information about disability rights was a cross cutting issue impacting all families. However, mother leaders noted social class differences. For example, the mother leader of networks 6 and 8 in São Paulo pointed out the difference between the two neighbouring cities across which the networks spanned, *'I say that they are two cities so close, and the reality is completely different.'* She further explained that,

> *'From [city 1], the mothers... maybe because she has a more relaxed socioeconomic background, she has more time to study, you know? She is looking for more information and [city 2] doesn't have it. So, I see that, for example, in [city 1] the person says, 'that's the law here' and tells you. If they think, no, that it is their right, they will go after it and they will look for a lawyer, they... [in city 2], it seems that the knowledge about what is offered to them does not reach them, they are fine and "I accept that because that's what it is".'*

The divide in access to information about rights and services was also reiterated by Mother 2.7 in Bahia, who discovered for the first time that she could schedule appointments and get advice about citizens' rights via a telephone consultation with the public defender's office. She lamented that, *'we don't have this knowledge. I could never have known that if you call 129* [the state's public defender's hotline] *you could get medical consultations…when we go to the clinic, there's no way to get them… these are things that are neglected.'* She further highlighted the critical knowledge gap for peripheral mothers, creating '*an environment where we can't talk about policies…there is no way to [do so]'.* She urged me to *'put in your report that it's like this: the policy means that peripheral mothers do not have the knowledge that other mothers who are not peripheral have, understand? …I'm certain that your report will highlight this thing here, how we are deficient in information.'* From these mothers' comments, as well as the observations of the mother leaders and professionals, I propose that the lack of diagnostic care and support that neglects to communicate families' rights creates a situation of vulnerability where mothers, and especially peripheral mothers, remain ignorant of their own and their child's rights. This undermines the rights-based approach to disability enshrined in law and public policy, as the denial of these rights in practice stems from neglect to inform rights-holders during the post-diagnostic phase.

Lack of emotional support

For some mothers, their emotional well-being was impacted by the lack of post-diagnostic care and support. However, most of the mothers involved in the study reported that they never received any sort of professional support during the post-diagnostic phase. Other research in Brazil shows that there is a lack of post-diagnostic support for mothers of children diagnosed with Autism, in the form of psychosocial support available via the SUS to help meet the mental health needs of mothers (V. C. R. da Silva & Silva, 2022). Mother 7.2 in São Paulo, whose son was born prematurely with Down syndrome and multiple health complications, described the emotional hardship she faced once her son had been discharged from the intensive care unit and the lack of psychological support during this period. She explained how *'he was hospitalised for four months and 15 days...then he left…it was very painful…'* She observed that '*This part of psychological support for mothers really doesn't exist…'.* For her, having formal support during this period would have helped her deal with the uncertainty around his life and future.

Similarly, the SUS psychologist noted the importance of providing information and emotional support, especially when mothers '*have a very distorted view… a very catastrophic vision that "ah, my son has this, so he will never improve, he will never progress".* She described how she worked with mothers to provide support in how they might approach things differently; '*not "improving", right, but an evolution*', highlighting the importance of a better understanding of the diagnosis for the child's wellbeing. According to

her, '*by not understanding the diagnosis and how it works, they end up getting frustrated and end up hitting the child. Many mothers have come to me, one told me, that they hit because they didn't understand.'* This was the only instance of physical violence against children by mothers being reported, and so it is beyond the scope of this study to establish the prevalence of this behaviour. However, other studies in Brazil have established a correlation between parental stress, lack of support and physical abuse towards children (Bérgamo & Bazon, 2011) and the increased vulnerability of children with disabilities to physical violence within their own families (de Barros, Deslandes, & Bastos, 2016; L. C. Moreira & Mouro, 2021), indicating that lack of professional support and information for family members could be key in preventing violence towards children.

Formal support - Professionals

All mothers in the study had significant experience with formal support from professionals in health, social assistance, or education services. While this support was valuable, the absence of comprehensive, high-quality services was also noted. Occasionally, mothers received multidisciplinary care from professionals within the same organisation, such as in specialist centres for people with disabilities, known as *multicentros*, which are part of the Specialised Outpatient Care in the Care Network for People with Disabilities within the SUS system. Although this was not the focus of the research, I visited a few multicentros during the research process to conduct interviews with professionals and for background research. These centres can include healthcare professionals working alongside social workers and education professionals. Some multicentros provided services like one-on-one psychological support or group counselling for parents, which were unavailable to most study participants. For instance, mother 5.1 in Rio de Janeiro described her positive experiences at a multicentro, stating, '*my support network today is in [neighbourhood] where they embraced [my son] in a way that allowed him to get daycare…I have nothing to complain about… they were the ones who taught me the whole process step by step with [my son]… Believe it or not, I got all the support I needed!'* That said, despite receiving good support, she had a very limited social network, relying on her teenage daughter for care respite since her husband had abandoned the family, and she had no one else to look after him.

It became evident through the research that the lack of holistic, non-medicalised, post-diagnostic care and both formal and informal support in general impacted mothers' mental wellbeing, due to the lack of information and support during the adjustment process. This reflects the impact of medicalisation of disability within the healthcare system, where healthcare teams focus narrowly on diagnosis and prognosis, relying on information dominated by biomedical, inaccessible and medical jargon, without addressing the emotional and social needs of families. Mothers' lack of information and support from non-medical professionals, such as social workers, could lead to anomie, as they were left without vital information regarding rights and services in areas such as social assistance and

inclusive education. Overall, the findings suggest that the biomedical model not only shapes how disabilities are perceived and treated in healthcare but also limits access to broader support. This underscores a systemic failure to disseminate crucial information effectively and the role of informal networks of mothers in addressing these gaps, which is to be further explored in the following chapter.

5.3. Access to services in peripheral areas

The second group of themes relate to access to services in peripheral areas. Access to healthcare services has already been touched on in the context of the diagnostic process, as presented in the first section. However, access to healthcare will be elaborated alongside access to education and social assistance services, which form the key public services featured in mothers' stories. Access to these services was largely experienced relating to the following sub-themes: lack of provision and affordability; denial and precarity; and the role of private healthcare.

5.3.1. Lack of provision and affordance - *'we are at the mercy of the SUS'*

Mothers' and children's experiences were shaped by both the absence of essential services in peripheral areas and, where such services did exist, significant barriers to accessing them. Following the conceptual framework presented in chapter two, I conceptualise this *absence*, either *of* or *access to* services, as 'contraction of the environment and the inaccessibility, unavailability, or negation of its existing set of affordances' (Dokumaci, 2019, p. 495). I further reiterate here the importance of quality in the measure of affordance, since access to poor-quality health services, for example, does not afford good healthcare. In addition, access to one service was often reliant on access to another, such as public transport, especially when services were located in other neighbourhoods and private transport was financially unviable.

Lack of provision and affordability, therefore, emerged as a key umbrella theme that linked experiences of access to services in a context of chronic denials of access within the periphery, or a constant state of *shrunken affordances.* This focus on the state of continual denial of affordances expands on Dokumaci's (2019) concept of 'shrinking affordances', which emphasises the process. I analyse here the implications of trying to promote the well-being of a child with a disability in such a restricted environment and how this shapes mothers' experiences. Using the framing of Nixon (2011), we can think of the impacts of the state of shrunken affordances as a type of slow violence that produces disablement and debilitation through state neglect of services or infrastructure. In the case of Brazil, this can be contextualised through the long-term chronic underfunding and dismantling of the SUS

(Mendes, 2013; Souza, 2020) and other public services that exacerbate inequalities experienced by communities in peripheral areas and regional disparities (Marques, 2019).

According to the Brazilian Ministry of Health, the Black population across the country are more likely to be solely dependent on the SUS; 67% of users are Black and 47.2% white, in comparison to 55.5% and 43.5% of Brazil's population, respectively (Ministério da Saúde, 2017). Dismantling of the SUS and other public services therefore disproportionality impacts these populations. Crucially, this form of violence is not always overt or direct but insidious, invisible and slow. I will attempt to explain in this section how chronic lack of service provision and affordability in peripheral areas, disproportionately impacts the Black population, women, children and people with disabilities, presenting this in four sub themes which interact but will be presented separately for the ease of analysis, as follows; poor provision and medical negligence; high complexity health services; transport; bureaucracy and waiting lists. In this subsection, I will draw on the online survey data alongside the qualitative data from interviews and conversation circles.

Poor provision, medical negligence

Poor provision, including overstretched services, was linked to medical negligence and delays in accessing healthcare. In some cases, this was related to delayed access to maternity care or postnatal care, especially impacting Black women in peripheral areas, which in some cases were reported as having caused children's disabilities. During a visit to a clinic for people with disabilities in Rio de Janeiro, staff noted that many children attending the centre acquired complex disabilities during or after birth, linked to poor healthcare attendance in the favelas where their families lived. Mother 2.9 in Bahia, who identified as a Black woman, said of her son's birth, *'the intellectual disability was caused... I blame the hospital because when I went to have him, I didn't even know it was going to be a C-section. And I did all the prenatal care, but when I got there, they took a long time to see me…he almost died in my hands.'* Whilst in other cases, mothers did not link medical negligence or poor service provision to medical racism, mother-leader 4 in Rio de Janeiro, attributed her son's Cerebral Palsy to a doctor's initial refusal to perform a necessary C-section. According to her, *'what caused my son's disability was perinatal anoxia due to a medical error',* explaining how she had heard the doctor saying that he did not perform C-sections on Black women, northeastern women and indigenous women. His initial refusal had resulted in a delay to the C-section procedure that was eventually performed, which she attributed to her son's disability.

Research consistently shows poorer maternal health outcomes for Black women in Brazil. For example, data collected between 2015 and 2022 shows that maternal death risk was twice as high for Black women as white women and was also associated with lower levels of education (Maria do Carmo Leal, Granado, Bittencourt, Esteves, & Caetano, 2023). Similarly,

other research shows that rates of obstetric violence[9], including comments like the one mother-leader 4 reported, were higher amongst Black mothers and those with lower levels of education (Graell, Morganti, Novo, Braga, & Carioca, 2024). Whilst there is a lack of research on the link between obstetric violence, access to maternal healthcare services and disability rates of children in Brazil, wider research shows access to maternal and neonatal health care interventions improves health and decreases risk of mortality and morbidity in both mothers and children (Lassi, Majeed, Rashid, Yakoob, & Bhutta, 2013).

For children needing ongoing medical care, mothers noted a stark lack of aftercare in the community following hospital discharge, which left them to navigate their children's care alone. Mother 5.3 in Rio de Janeiro expressed frustration that her seven-year-old daughter was discharged following an electrical accident in their home that had led to her losing several limbs. She was told to go home and provide aftercare herself, or go back to the family health clinic, but felt, '*I didn't know anything. I didn't even know where to start*'. She described minimal visits from community health workers (CSW) [PT: agentes comunitários de saúde], who had only visited twice in the two years since the accident, indicating a gap in aftercare *'for people who live in the community,* [which] *is very poorly supported.'* Community health workers are partly responsible for implementing Brazil's Family Health Strategy, which includes rehabilitation, harm reduction and referral for further treatment as outreach for the primary healthcare units, including the family health clinics (Secretaria de Comunicação Social, 2024). However, prior research indicates that CWS can inadvertently reproduce inequalities in access to healthcare owing to power dynamics and poor training within an overstretched healthcare system (Nunes and Lotta, 2019; 2023).

High complexity health services

Access to complex health services at the tertiary level of the SUS[10] is particularly relevant to the children of mothers in the study, as they were more likely to rely on these services. The lack of service provision reported by mothers aligns with large-scale research across Brazil showing that high complexity public health services [PT: Unidades de Saúde de Alta Complexidade] within the SUS are generally concentrated in urban centres that tend to be dominated by the majority white higher income population (Tomasiello et al., 2021). The same study showed that whilst the low-income and predominantly Black population access primary healthcare services[11] within the SUS more frequently than the white population, they are less likely to be able to access complex healthcare services (ibid). Interviews underscored this disparity, with the NGO-run service manager interviewed in Bahia noting,

[9] defined by the UN Special Rapporteur for Violence Against Women as 'violence experienced by women during facility-based childbirth' (UN General Assembly, 2019).

[10] including services which provide specialist treatments or intensive therapies such as physiotherapy, cancer treatments and specialised surgeries.

[11] namely via primary health units [*PT: Unidade Básica da Saúde (UBS)]*

'around these neighbourhoods here, there is nothing in terms of SUS [national healthcare system]. There is no such thing as physiotherapy.' As a result, families were faced with limited or no options for accessing certain high complexity services, depending on the locations where they lived and access to transport, which will be discussed later in this section.

For 75% of mothers who filled out the online survey, private healthcare, to be discussed in the following subsection, remained unaffordable. Mother 5.4 in Rio de Janeiro explained, *'we can't afford the private sector, right? So, there's no way to pay for it, how would it come to be…?'* She further noted that some people use the disability benefit to pay for private healthcare, but for those who cannot get benefits, they are left without the means to pay for private services*, 'so, it gets difficult, we are left at the mercy of the SUS.'* Being left at the mercy of the SUS indicates the level of precarity of access to healthcare that families experienced via the SUS. Rather than being guaranteed universal access to healthcare as per the Brazilian constitution (Brazil, 1988) and law (Brazil, 1990), according to the experiences of mothers, access was not guaranteed owing to the shrunken affordances of the healthcare system, especially in peripheral areas.

However, the precarious access to the SUS did not necessarily mean poor quality healthcare. Although some mothers reported negative healthcare experiences via the SUS, many others reported positive ones, indicating that it was highly valued when quality healthcare could be accessed. A mother in Bahia who had had negative experiences in accessing therapies via a private health plan said that she was '*trying the SUS, because I have seen that SUS professionals are interested in training themselves to have a good education and to provide good care*.' According to her, *'it's not the SUS professionals who are in a bad way, it's the system…the demand itself.'* Reliance on the SUS was generally precarious because universal access to quality healthcare could not always be guaranteed.

Reliance on the SUS could be linked to poor health outcomes for some children and was described by mothers and professionals as a system stretched beyond its limits, resulting in barriers to necessary therapies that impacted children's health and development. Mother leader 6 in Minas Gerais explained how her son with CZS was unable to access all the therapies that he was recommended, *due to demand*'. She explained how, although he was prescribed therapeutic treatment twice a week, '*in the municipality I can only get one. So, he goes this once*.' When describing the impacts of the lack of access to the recommended healthcare for children with CZS, she explained '*the child develops slowly or does not develop at all'.*

The impacts of a lack of access to high complexity health services for children with CZS could also result in serious health decline and death. According to the mother leader of the community NGO for children with CZS in Bahia, *'we had about eight children die during the*

pandemic. Not because of Covid, but other things, lack of care, respiratory care, some who were unable to arrive to get care, ultimately.' This highlighted the extreme end of scenarios of lack of access to high complexity healthcare due to the failure of the state to guarantee universal access. I propose that the failure of the state to guarantee this access for specific communities and populations is approached as the active creation of debility (Puar, 2017) and death through targeted, yet slow violence (Nixon, 2011) and marginalisation. The added value of framing failures of the state through debility and slow violence is that it highlights the intentionality in the debilitation of certain populations through neglect. The examples included here were maternal and neonatal care and high complexity healthcare, including rehabilitative and respiratory care, which I will further elaborate on in the upcoming section on private healthcare.

Transport

The issues in physical access to services emerged as a theme during discussions about access by mothers who lived in peripheral areas, which were often located far from the healthcare services clustered in rich urban centres (Tomasiello et al., 2021). Therefore, the lack of access to public transport within peripheral areas compounded the barriers to accessing SUS services. Inaccessible public transport either bars access entirely or forces families to find expensive alternatives. Mother 7.1 in São Paulo explained how, since local buses were inaccessible for her daughter's wheelchair, '*we end up spending a lot on Uber and by spending on Uber we can't…buy a car'.* Financial issues were a key source of stress for this mother, who had been forced to return to work to pay for a health plan for her daughter since she had not been able to access a diagnosis or healthcare for her via the SUS. Similarly, the NGO worker interviewed in Bahia noted that the lack of access to high complexity health services such as physiotherapy was linked to the lack of accessible transport; '*Transport? There is no adaptation.'*

During the conversation circle in Rio de Janeiro, mothers discussed how, despite a free disability transport card [PT: *passe livre*], delays in accessing the cards, lack of access to disability benefits and poor door-to-door bus route coverage impacted families accessing healthcare. Mother 5.3 explained, ***'****I applied [for the transport card] in January. It's August now, and it hasn't come through yet.'* Mother 5.4 agreed, relating her similar experiences, *'I went looking for…the free passes for the subway, train and bus…I waited almost seven months.'* Mother 5.3 then reflected on the impacts of following up on healthcare for her daughter, who had lost part of both feet during the electrical accident. '*How would I get there? How would I leave the house? Because I live in [neighbourhood 1], the family clinic is in [neighbourhood 2]* [approx. 15km apart]. *[daughter]…has three toes left.'* Mother 2.2. in Bahia also described how the cost of transport and her own disability had previously meant *'sometimes [son] wouldn't go to the doctor because I didn't have transportation'*. Eventually, she was able to get a free travel pass but only after much struggle. These instances

demonstrate how the shrunken affordances of one service can impact access to another. I highlight how inaccessibility to public transport is linked to the political exclusion of people with disabilities from other parts of society (Avery, 2017), which is a key element of the debilitation of certain populations (Puar, 2017).

Bureaucracy and waiting lists

Like the issues of accessing diagnosis already outlined, high levels of bureaucracy linked to long waiting lists also typified the experiences of mothers throughout the process of accessing other forms of state support, including healthcare and social assistance. As mother 1.3 in Bahia put it, *'there are rules of the institutions and often these rules do not match our reality.'* This inaccessibility of systems and lack of ways to 'speed up' the process of access led to families facing long waiting lists for services, often via the National Regulation System (SISREG) or the State Regulatory System [PT: Sistema Estadual de Regulação (SER)]. Indeed, the SISREG system has been nicknamed by Brazilians, 'the line of death'. The NGO worker interviewed in Bahia succinctly summarised: '*If you stay in regulation [SISREG], you die*'. Data collected from the quarterly reports on the SISREG and SER showed that in October 2024, SISREG had 427,000 patients waiting in SISREG in Rio de Janeiro, with waiting lists for different services increasing on average by 401% between 2023 and 2024 (Grinberg & Bustamante, 2024). The longest wait times published in an analysis of the report by O Globo were for initial appointments for paediatric intellectual rehabilitation[12], on average 304 days in 2023 and 251 days in 2024 (ibid). The lack of operational clarity and waiting times all contribute to the negation of the 'existing set of affordances' (Dokumaci, 2019, p. 495) that, on paper, are provided by state assistance systems, therefore reducing what these systems afford families in terms of universal access.

Because of these shrunken affordances, Brazilian systems have developed to operate with a degree of informality, which has enabled professionals and users to navigate the lack of efficacy of these systems and increase their affordability. For example, healthcare professionals will sometimes 'make up for' bureaucracy and lack of operational clarity that prevent children from accessing specialised care by using their specialist knowledge of system operations and relationships with other professionals to speed up, bypass or shortcut, therefore considerably improving access (da Silva & Moreira, 2021). This was similarly noted by the NGO worker in Bahia, who described how this was a major function of the services they provided to families in the area, acting as an intermediary with state assistance systems, including healthcare and social assistance, by using personal relationships to circumvent bureaucracy. She explained how she had recently used a relationship with a local governor to speed up a referral for an MRI scan for a community

[12] Includes referral to multidisciplinary teams including healthcare staff such as neuropaediatricians, psychiatrists, paediatricians, occupational therapists, nutritionists and physiotherapists as well as social workers.

member. '*Waiting eight months and you solved it in a matter of minutes." That's how it works*.' Dokumaci refers to physical acts of assistance between people using the concept of *people as affordances* (2020). I suggest here that by expanding the concept beyond physical acts of affordance creation, we can see how people, such as healthcare professionals, can also act to create affordances to and within systems in a perpetual state of shrunken affordances owing to underinvestment. This concept will be applied to mothers and expanded on in the next chapter.

Using the informality of the system to circumvent the lack of affordability was not always successful for two reasons. Sometimes, it did not always work due to high demand. Mother 7.2 in São Paulo described how her son's speech therapist had intervened to prevent him from losing his place after a long absence due to illness, which had been successful. However, when the speech therapist tried to intervene on her behalf to do the same with his physiotherapy, it did not work due to the long waiting lists. This indicates the precarity of this method of access. Secondly, this avenue of access was unavailable for mothers who were not part of these informal networks, i.e., who did not have a willing professional or NGO to act as an intermediary. During the conversation circles, mothers across all research sites repeatedly related that they '*tried, but couldn't*' [Mother 7.1, São Paulo] access social assistance or healthcare – '*through the SUS doesn't exist, we couldn't do it, it was nothing*' [Mother 2.2., Bahia], indicating that, whilst for some mothers, in some situations, the use of social ties and the informality of the system had worked to their advantage to create affordances, other mothers were not part of such networks or had been unsuccessful. In summary, reliance on public services for the majority of families who took part in the study defined their experiences of access to state support. The following section will examine how access to private healthcare impacts families' experiences.

5.3.2. Having financial resources to access private healthcare – *'You can clearly see the difference in the children who do.'*

Healthcare is accessed via a two-tier system in Brazil, consisting of the SUS and private healthcare plans, which have low-cost options. Although private healthcare is not superior, healthcare plans offer easier access to some services, facilities, professionals and technologies (B. Silva et al., 2022). Healthcare plans are also correlated with greater utilisation of healthcare services overall (Coube et al., 2023), and, consequently, the two-tier system undermines the universality and equality principles on which the SUS is built (Massuda, Hone, Leles, De Castro, & Atun, 2018). Brazil is one of the biggest markets for private health plans, which range from basic and low-cost plans marketed to those on lower incomes to more sophisticated and expensive plans marketed to those on higher incomes. Around 25% of the population had access to a healthcare plan in 2022, although 70% of this

access is assured as an employment benefit (Agência Nacional de Saúde Suplementar, 2022).

As the research focused on families from a lower socioeconomic position, most relied entirely on the SUS for healthcare, as explored in the previous section. Some mothers mentioned using healthcare plans, although this only accounted for 15% of those who completed the online survey. The most commonly mentioned healthcare insurance company during conversations with mothers was Hapvida, which is considered to provide some of the country's cheapest plans, from 128.23 BRL per month (less than 18 GBP per month) and provides most coverage in the north and northeast of the country. Moreover, other research indicates widespread racial and geographic disparities in access to private healthcare. Dependence on the SUS is linked to the low levels of income of the Black population, which makes them less likely to be able to access private healthcare insurance (Ministério da Saúde, 2017). This was consistent with the low coverage of the online survey respondents by private healthcare, as previously mentioned. Even for those with health plans, the complexities of navigating bureaucracy or having to resort to judicial processes to get plans to cover certain healthcare services remained a barrier to access or resulted in long delays.

The difference in access that some healthcare plans provided to relieve reliance on the SUS was stark, particularly in the case of children with Congenital Zika Syndrome (CZS), for whom medical intervention and therapy are often life-preserving. The following excerpt from the mother-leader of the network for children with CZS in Bahia demonstrates this, when asked about the differences she perceived in access according to the socioeconomic position of the families attending the NGO she had set up.

> *'Of course, the difference in access, right? You can clearly see the difference in the children who do - my daughter, for example… I'm in a very privileged place. My daughter, the Health Plan provides care every day. So, she had a very important problem… very serious, but you see that there are some things - for example, the children have a lot, a lot of respiratory issues. You notice that children who died, there were deaths - this respiratory part is important. My daughter goes [for respiratory therapy] twice a week, three times - she's never been hospitalised. And there we see several children being hospitalised all the time. Because it's not a service that you can easily find anywhere.'*

She is explaining here how the higher cost healthcare plan that she can afford has provided her daughter, who has CZS, with a higher level of access to respiratory therapy, which she attributes to her lack of hospitalisation. In comparison, she reflects how the other children with CZS, part of the same network, who did not have access to these therapies, have higher rates of hospitalisation and mortality. It is assumed, therefore, that negative health

outcomes, including mortality for peripheral and Black children from lower socioeconomic backgrounds, are directly related to access to certain healthcare services through healthcare plans.

Dual use of the SUS and private healthcare

Some mothers benefited from dual use of Brazil's public (SUS) and private healthcare systems, though for many, private plans served only as emergency backups. As mother leader 5 in Minas Gerais explained, *'[Son] also has a plan, but I use SUS. The plan, is that he will use more for emergency things, when we can't wait in the SUS line. Considering* the long wait times for certain healthcare services, there appeared to be an understanding that healthcare plans were necessary for emergency access. She further explained how even when families had healthcare plans through employment contracts, '*they don't stop using the SUS, which is a larger support network.'*

While dual system use is common among those who can afford it, it creates complications. The lack of integration between public and private systems leads to bureaucratic delays, particularly in referrals and documentation (B. Silva et al., 2022). Some mothers were able to access therapies denied by SUS through private plans—but only after long battles with insurers. Others paid out of pocket or went without. One mother in São Paulo recalled paying a speech therapist for two years because the insurance wouldn't cover it. In Bahia, mother 2.8. said, *'Hapvida doesn't work in any way, in terms of therapies, in the lives of autistic people'.* This indicates that whilst healthcare plans had complex bureaucratic systems that had to be battled for access to certain services, there was inconsistency in access and coverage.

The findings indicated that dual use of public and private systems can create confusion and barriers, particularly regarding access to therapies and necessary documentation. Many families rely on the public health system (SUS), while low-cost private health plans like Hapvida are often insufficient to cover access to recommended (including life-saving) therapies. Coverage varies by plan cost, reinforcing socioeconomic disparities that, as mother leader 2 in Bahia noted, can determine whether children live or die.

The reflection of mother 6.2 in São Paulo reveals awareness of the realities of the periphery and privatisation of healthcare, *'like it or not…the biggest disorders are in the peripheries. The purchasing power greatly influences the disorder, the child's development.'* Similarly to Mother leader 6 in Minas Gerais, she reflects here on how the 'development' of a child relies on therapies that can only be acquired through private healthcare, which is unaffordable for many peripheral families. I draw here on the work of Lauren Berlant (2007), who draws links between medicalisation and privatisation of healthcare, which reinforces personal responsibility for health (based on Foucault's ideas of biopower), and, I add here,

the related concept of development, requiring financial investment in one's own (or one's child's) health. Furthermore, Puar (2017) links the neoliberal privatisation of services to her concept of debility, which is caused by financial strain and debt that contribute to processes of debilitation. We see here, in the case of children who rely on expensive life-saving treatments, that their survival is based on their family's ability to invest in their health, which furthers the process of debilitation through financial extraction.

5.3.3. Denial, precarity & debility - 'it's not living, guys, it's surviving'

The affordance of systems to mothers and children was also impacted by the denial or inadequacy of social assistance, including disability welfare benefits such as the BPC, which created and exacerbated existing financial precarity for families and reduced access to other services, such as private healthcare. Earlier in this chapter, diagnosis was presented as a gateway to access other services and state support. In this way, access to welfare was medicalised through its regulation via diagnosis and disability evaluation processes. We can draw inspiration for analysing this denial and inadequacy from two concepts. Schalk (2022) uses an intersectional framework to talk about how the medicalisation of welfare in the US is used as part of an ableist, racist and sexist justification to control, define and vilify mothers of colour as a drain on public resources. We can also view the denial of social assistance through the lens of slow violence (Nixon, 2011). For example, Mills and Pring (2024) use slow violence to analyse the impacts of the welfare policies and welfare reforms in the UK and how the slow and harmful effects of policy implementation which led to the deaths of an unknown number of benefits claimants, because of the government's reluctance to investigate or publish information. Whilst the situation in Brazil is very different to that of the US and the UK, we can apply the same ideas to think about the vilification of Black mothers of children with disabilities and the lack of state support afforded to them.

Analysis of social assistance and welfare is especially relevant in light of new austerity measures that threaten to restrict the eligibility criteria for accessing the BPC (PL 4614/24), approved by the Brazilian Senate in December 2024 and awaiting presidential approval. The changes were justified using reasons which echo the austerity measures implemented by the UK's Conservative government from 2010 onwards to tackle 'benefit fraud' that particularly impacted disabled people. Since the Black, peripheral population with disabilities, including single mothers on behalf of their children, are more likely to claim BPC, we can view the excuse of combating benefit fraud as part of the vilification of this population. Furthermore, although the proposal to restrict the benefit to only those who are classified as having 'moderate' or 'severe' disabilities was rejected, other changes were approved (Agência Senado, 2024). These included the need for a medical diagnosis that categorizes disability according to the ICD; a requirement to annually update the online

Registry System [PT: CadÚnico] for receiving state benefits by attending a CRAS (Social Assistance Reference Center); obligatory regulation of biometric data; and changes to the minimum family income calculation to exclude discounts that are not other state benefits (Ministério do Desenvolvimento e Assistência Social, 2025).

These changes can be seen to further medicalise disability and disability benefits by tying eligibility to a medical categorisation system that does not take into account the social environment within which a person with a disability is located. Furthermore, by more frequently regulating BPC through an online system and CRAS, those who are less likely to have access to the internet, lower levels of education and digital literacy and live far from CRAS centres, namely those living in peripheral areas, are likely to suffer most from these changes. The labyrinthic systems through which they must pass in order to gain access, as outlined, as well as the risk of being outright denied access, plus the inadequacy of the support even when it can be accessed which place families in a situation of financial precarity, can therefore be seen as part of a system of slow violence (Nixon, 2011) that is designed to deny access and slowly exacerbate precarity and poor health.

Delay and judicialisation

Delay or denial of access to benefits and services was a recurring theme, and mothers shared detailed accounts of negative experiences during disability evaluation and application processes. As noted, evaluations are not standardised, which requires mothers to repeatedly prove their child's eligibility for different services and benefits. In the Bahia conversation circle, one mother explained that she couldn't take a job because of her daughter's intensive therapy needs, yet the child's only benefit had been denied three months earlier. She recounted how her daughter consistently failed to meet the evaluation criteria, despite clear needs, stating, "*She doesn't pass. She arrives there, she doesn't pass… And I've already heard it, I'm already walking, my mind is already tired.*"In the online survey, 32.6% reported their child being denied access to therapies, 10.5% had been denied a health plan, 15.8% had been denied access to Minha Casa Minha Vida[13], and 10.5% had been denied access to Bolsa Família[14]. Only 26.9% of those who registered had children receiving the main disability benefit, the BPC, though 22.1% reported experiencing denial of the BPC.

Those who had access to the BPC reported they had managed to get access after a long bureaucratic process, multiple denials, and sometimes, resorting to judicial processes. For others, judicial processes were inaccessible, so they remained without access, despite the likelihood of being eligible. National level research shows that the average wait time for a

[13] Social housing programme for low income families.

[14] Conditional cash transfer programme for low income families.

disability evaluation for the BPC increased from 1.25 months in 2016 to 6.61 months in 2021 (Ministerio da Mulher da Família e dos Direitos Humanos; Secretaria Nacional dos Direitos das Pessoas com Deficiência, 2021). The same study notes that the BPC has been judicialized because of the high rates of administrative decisions that deny access, making it one of the highest demands within Brazilian courts. Rates of judicialization have increased steadily from 1996, at 0.7% of successful claims, to 49.76% in 2020, in accordance with the reduction in successful claims via the regular administrative process (ibid). These statistics indicate that at least half of all eligible BPC claims are denied via the regular administrative process. These denials are indicative of intentional shrinking of the affordances of the environment, whereby rights on paper are made inaccessible through slow bureaucratic processes (Dokumaci, 2019). I draw a comparison here with the UK context, where Pring and Mills (2024) note that these 'delay tactics' are a key feature of slow violence (Nixon, 2011), employed by the UK government to distance itself from the harms of its austerity policies. By judicialising the BPC, the Brazilian government also distances itself from the responsibility of harm towards its citizens with disabilities and their families.

Created precarity

The implications of denied access were the creation of or worsening of the financial precarity of families, which exacerbated the negative experiences of mothers. Some mothers who took part in the research were not eligible for the BPC because they earned above the threshold[15]. Although, many of these families report experiencing financial hardship since the threshold is extremely low[16]. Although there is a proposed Bill (4,680/2024) to increase this by 25%[17] for beneficiaries who rely on daily assistance from a carer, the government acknowledges that this amount would still not remunerate the full cost of a carer, valued at around four times the amount of the proposed increase, which may or may not be passed (Agência Senado, 2025). Mothers who earned above this threshold still reported financial difficulties because of the extra costs associated with their child's disability, including having to pay for private healthcare or paying out of pocket for assistive devices like orthosis because they were unable to access these via the SUS. The BPC is an individual benefit that is not designed to cover the loss of income related to caring activities. Yet, it must cover two people's 'income' (beneficiary and carer) on only one minimum wage salary, hence keeping the family in relative poverty (Medeiros, Diniz, & Squinca, 2015). We can frame this as created precarity, whereby the financial limitations of the benefit cause financial stress for mothers, who must account for their own loss of

[15] One quarter of a minimum wage on average across all members of the household, approximately 50 GBP or 60 USD per month

[16] For single mothers with one child, this would be around 100 GBP or 120 USD to cover all expenses, including extra costs associated with a child' disability.

[17] A proposed increase of BRL 379, approximately GBP 51 or USD 62 per month.

income and their children's basic needs on a benefit designed to absorb the extra costs of disability.

The case of mother 7.2 in São Paulo, of a son with multiple disabilities and health needs, illustrates how the complexity of interaction between financial hardship, caring responsibilities, discrimination on grounds of disability and race and the inadequacy of the social assistance system creates precarity. Although formally employed as a primary school teacher, she struggled to afford the extra costs associated with her son's medical and disability needs following the denial of access to these via the SUS. She therefore used her salary to pay for private healthcare, medication, therapies and his special diet. On seeking state support, her needs were dismissed by a social worker, who *'said that I didn't have a problem…[she] said, "You work, you can help your son... I have a huge line of mothers here who don't work, who have no income and who are in poverty'",* even though her *'salary isn't enough'* to cover the additional expenses. She linked her situation to her identity as a Black woman with heavy caregiving and financial burdens, describing being harassed at work for taking time off for medical appointments, despite her absences being justified. *'Especially for us, women, Black, it is much more complicated, more demanding.'* Furthermore, she had been denied approval by her employer and the courts to reduce her working hours in line with Law 13,370/16[18] (Agência Senado, 2016). Her observation was that anti-discrimination laws, such as the one for family carers, are '*beneficial for some people, not for others. In this and all cases, justice works like that'.* Her experience, like those of many others, underscored how denial of access to rights and support often occurred without clear justification, reinforcing structural inequalities rooted in race, gender, class, and disability.

In cases where a child did receive the BPC, the inadequacy of this income to cover the needs of the family and the restrictions this placed on families to earn extra income in case it pushed them over the eligibility threshold[19] was mentioned frequently across all research sites. Mothers who received the BPC noted that it had left them and other mothers they knew in a state of poverty. Mother 5.1 in Rio de Janeiro recounted, *'I'm alone with two children. I live on LOAS [benefits] …the little pension that the father sends, and so every month is tight. Every month.'* She also spoke about this as a common experience across mothers' network 9*: 'there are mothers in our group who pay rent and survive because it's not living, guys, it's surviving, on benefits.'* Similarly, mother-leader 5 of network 5 in Minas Gerais noted that despite receiving the BPC and other social assistance benefits, mothers in her network could not always make ends meet. She described the BPC as *'a value that does not work. The accounts don't add up,'* that left mothers asking, *'What do I spend? What do I pay? One salary is not enough.'* As a result, mothers were regularly reliant on charity from

[18] Guarantees reduced working hours to federal public servants with caring responsibilities for a family member with a disability.

[19] Financial eligibility threshold for receiving the BPC is average household income of less than ¼ of a minimum wage. In 2025 this is BRL 375.50, which is approximately 50 GBP or 60 USD.

friends, family and local NGOs to cover their basic costs. She explained how *'if it wasn't for a neighbour or family helping, it wouldn't work. It doesn't pay the bills, no. You can't put food in the house.'* It is therefore clear that the calculation of disability benefits eligibility can seriously disadvantage families with higher outgoing costs associated with their disabilities.

Dependency

Finally, professional and mother-leader interviewees noted that familial disability policies lead to a dependency of other family members, but principally mothers, on their child's benefits, namely the BPC. Carers for people who receive it are not allowed to work, or else they lose the benefit, which creates dependency through loss of skills and exclusion from the job market and education. We can draw on the work of Gesser et al. (2022) here to better understand the impact of familial policies in Brazil. They argue that familism and ableism work together to make care belong in the private sphere rather than being framed as a responsibility of the state via social protection or a question of rights and justice, which reinforces intersectional discrimination along gender, race and class lines (ibid). Familial policies therefore have multiple negative impacts, including reducing people with disabilities to recipients of charity, reducing the autonomy and choice of both the carer and the cared for, and creating a dependency of the family on disability related benefits as well as a fear of losing them. Furthermore, familial disability and care policies disproportionately impact Black, peripheral communities, who hold a lower socioeconomic position in Brazilian society and are less likely to have the financial means to outsource care.

Mother leader 4 in Rio de Janeiro noted that many mothers had given up work or education because of their caring responsibilities and had lost skills to enter the job market, even when their responsibilities ended. Their financial reliance on the BPC led to financial instability when children died, for example. She observed that,

> *'the INSS [benefits] system is very flawed. It gives money to your son until the last day of his life. But disability stops the person. Both the disabled child and the person caring. That, you can put in your report. And then your child dies today, tomorrow there are no more benefits. And then you're starving because you didn't learn to take care of yourself.'*

Whilst there is a pending Bill (4764/20) to convert the BPC into a pension for any dependents or informal caregivers on the death of the beneficiary (Agência Câmara dos Deputados, 2021), until, and indeed *if* this is passed, the current situation of dependency and precarity remains the same. I argue here that the slow pace of approval of improvements to the existing benefits laws, which often takes years to go through the Brazilian legislative proposal process, can also be interpreted as a delay tactic that forms part of slow violence (Pring & Mills, 2024; Nixon, 2011). Whilst these processes slowly

unfold, families languish in severe situations of created precarity, which leads to debility. For example, financial precarity because of the inadequacy of benefits also plays a crucial role in limiting access to healthcare.

Denial as debility

Continuous denials of access to state support, lack of time and the impacts of caregiving contributed to the debilitation of mothers; a key theme related to the gendered and racialised economy of care. From the online participant survey, 50 per cent identified themselves as a solo caregiver, and one-third said they had no daily help from another person in their child(ren)'s care. Williamson et al. note that familial welfare policies in Brazil lead to a chronification of gendered homemaking exacerbated by the COVID-19 pandemic and erasure of care infrastructure (2023). Many mothers' lives were therefore limited to care within the home, focused on their child's needs above all else, including their own healthcare needs. Mother leader 2 in Bahia described how '*mothers…are mostly alone to take care of everything, to live at home, right, to take care.'* This chronic, home-based caregiving limited the time available for mothers to take care of themselves. For example, the lack of time and alternative care for children impacted mothers' ability to seek healthcare for themselves, in addition to difficulties in getting medical appointments because of the shrunken affordances of the health system where they lived. Mother 2.3 in Bahia explained, '*my day is 24 hours with my son. This is a huge burden for a single mother…We can never get sick…if we get sick, who will take care of our child? There's no one*.' This had impacted on her own health, exacerbated by the shrunken affordances of the healthcare system, *'I have a thyroid problem...I can't get an appointment with a [doctor].'* Ultimately, this forced her to prioritise her son's health over her own, as she admitted, *'even though I'm sick, I'd rather be sick than my son.'*

The lack of support mothers received in an environment of shrunken affordances, especially in the case of single mothers, was also clearly linked to mothers' mental health. Mother 2.3 in Bahia, further shared, *'there are moments when I cry at home, when I feel distressed, when I feel uncertain… I would like a minute, a few hours for us to have some leisure time, so we could go to the cinema, go to the beach, take a shower. We don't have that time.'* Mothers across all research sites expressed distress at the lack of time for self-care and leisure because of the demands of their child's care and the time taken up by the struggle to access support and services.

Mother 6.1 São Paulo described how the lack of time means, *'we don't stop to analyse all of this, because…we get so..."look at what my child needs". We're like, "oh, he's missing that! Oh, got to go after that!" So, we end up forgetting to look at our side.'* Likewise, for Mother 2.3 in Bahia, her experience was '*a life…of giving up one thing to get another*'. This 'giving up' on one's own needs can be seen as a feature of debility that Puar (2017, p.16) describes

as ‘endemic, perhaps even normative, to disenfranchised communities…a banal feature of quotidian existence.’ The normativity of debility in the periphery can be seen as a consequence of a system that does not provide affordances for both mother and child. Forcing mothers to prioritise their time on creating affordances for their children to ensure, firstly, their survival and, hopefully, their wellbeing, to the detriment of their own, therefore becomes invisibilised as part of the role of disabled motherhood in the periphery. Their banal actions are thus not seen as exceptional and certainly not activist.

5.4. Chapter summary

In this first chapter of analysis, I have discussed how mothers experience disability narratives and information, as well as access support in peripheral areas. Their experiences are marked by race, gender and disability, not in the way it is understood through the biomedical model dominant in Brazilian systems, but in the way that Dokumaci describes as,

> *‘when the environment contracts and becomes affordance-less, no matter where that “less” comes from—whether it is a barrier, an ableist habitus, or the experience of chronic pain, disease, or debilitation.’* (Dokumaci, 2019, p. 511)

Considering the extreme constriction of peripheral environments through systems that categorise and exclude, medicalise, and debilitate mothers *alongside* their children, allows us to reiterate the potential of a political/relational framing of disability (Kafer, 2013) that goes beyond an identity based, binary understanding of disability that are also dominant in disability studies and disability activist spaces. Whilst experiences of carers have recently been recognised by the UN committee on the Rights of Persons with Disabilities as ‘discrimination by association’ (a description I do not disagree with), I argue that a siloed human rights framing fails to capture the political nature of when and how discrimination occurs, as well as to whom and why.

I do not mean to suggest here that all parents or primary caregivers of children with disabilities experience disability or debilitation in this way, nor that their experiences should be prioritised above those of people with disabilities themselves. Instead, I mean to highlight the importance of an intersectional analysis which demonstrates how, in environments of shrunken affordances the impacts on those considered traditionally as ‘disabled subjects’, in this case the children, can spill over to also impact those *responsibilised* for their care, wellbeing or normalisation, in this case (usually) mothers in peripheral areas, who are more likely to be racially and socioeconomically marginalised.

Whilst individual rights to disability services and support exist on paper in Brazil, the realities of access described by mothers in peripheral areas indicate that there is systematic

exclusion of peripheral populations from accessing those rights, including information that those rights exist, in practice. I argue here that the dominant biomedical, binary narratives and approaches to disability taken by services and systems serve to reinforce this exclusion and further shrink the affordances of provision. Mothers' and professionals' stories demonstrated how shrunken affordances to one service or system can impact access to another, resulting in a cycle of exclusion that disproportionately affects children with disabilities and their caregivers, who are already subject to 'shrunken worlds of possibility' (Dokumaci, 2023, p.95). For example, it was demonstrated how a lack of access to information about rights and mechanisms to protect against discrimination leads to exclusion of children from school, impacting mothers' affordances to paid work. Likewise, the lack of affordances of the public transport system bars access to healthcare.

Furthermore, I have sought to demonstrate how the linked shrunken affordances of environments and systems can result in the debilitation of mothers and children (Puar, 2017) – barring or delaying access to information, healthcare and essential support and resulting in poor health and mental health outcomes, children's delayed development, worsened impairments and in some cases, children's deaths. This chapter further highlighted the impacts of familial welfare policies that undermine the autonomy of those who provide and receive care as well as systematic discrimination along lines of race, gender, socioeconomic status, geographic, age and disability factors. The narratives emerging from this research therefore reflect a broader struggle against intersecting systems of oppression, where access to support is deeply intertwined with issues of race, socio-economic status, and defined by slow violence (Nixon, 2011).

This complexity underscores the need for a comprehensive understanding of how the biomedical model influences perceptions and treatments of disabilities within disability service and support systems, limiting the broader support available to families. The findings further indicate a critical need for improved communication and education around disability rights and services. There is an urgent requirement for healthcare and social services to collaboratively ensure that mothers are informed about their rights and available support systems. Addressing these gaps in communication, education and service provision is essential to empower families, reduce discrimination, and promote a more holistic approach to disability in Brazil. The following chapter will explore how these gaps, present in a context of shrunken affordances, are actively resisted by mothers through various strategies of microactivism.

Chapter 6 – Microactivist performances

6.1. Introduction

The previous chapter presented some of the main themes that came out of the empirical data collection, focusing on how disability narratives, information and access to support and services shape the experiences of mothers of children with disabilities in peripheral areas. The lack of access that mothers and children have was analysed through the concepts of shrunken affordances, adapted from Dokumaci's interpretation of affordances (2019), debility (Puar, 2017; Williamson, Engel, & Fietz, 2023) and slow violence (Nixon, 2011). The findings indicate that shrunken affordances in the peripheries limit access to essential services, support and information. Therefore, these shrunken affordances create a myriad of barriers that form part of a complex system that contributes to the debilitation of both mothers and children by denying them the affordances to good health and wellbeing, socioeconomic security and education.

In this chapter, I explore how mothers individually respond to these experiences of shrunken affordances in their daily lives and regular battles on behalf of themselves and their children with disabilities. Using the conceptual framework that draws on Dokumaci's (2019) concepts of microactivist affordances and people as affordances (2020), I analyse mothers' individual actions to address and resist failures of the state to provide access to information, services and support in peripheral areas alongside context from the wider literature. In particular, I look at how the restrictions and denial of access described in the previous chapter lead to resistance and how mothers are motivated to struggle for their children's rights. The conceptual framework is applied to mothers' individual and family-level 'struggle' to reveal additional actions beyond typical 'mothering', including self-education to counteract the lack of information about their rights and use this knowledge to create affordances to systems designed to exclude their children.

6.2. World-(re)imagining, self-education & fighting the system

In this section, I aim to demonstrate how, in a context of shrunken affordances, mothers' individual actions necessarily go beyond care acts and extend to other actions necessary to create affordances for their children to ensure their needs are met. In the previous chapter, barriers to accessing information and services were linked to negative experiences reported by participants, which resulted in impacts on the health and well-being of mothers and children. Naturally, mothers resisted negative narratives and instances of discrimination in what was described by many as a 'struggle' [PT: *luta*]. This term was used to describe both individual and family-level struggles, whereby mothers focus on the struggle for their own

child, but equally to talk about a collective struggle, which I will expand on in the following chapter, focusing on microactivist networks. Drawing on Dokumaci's work (2019, 2020), I conceptualise this as a struggle to build habitable worlds by creating affordances within an environment of shrunken affordances. I will, additionally, apply the lens of microactivist performances to analyse mothers' individual struggles more in depth.

McLaughlin and Goodley outline three 'types' of parents of children with disabilities (2008) within the UK context, which may be helpful in this analysis. They include, 1. the professional parent, who takes on technical (often medical) knowledge about their child's condition that out-shines that of professionals involved in their care; 2. the allied parent who has a change in identity, developing a humanised approach to disability that accepts and celebrates diversity whilst questioning injustice and societal norms, and; 3. the governed parent, subject to constant governance via health and social care systems that judge parental competence (ibid). I argue that, whilst some parents do 'fit' neatly into one of these three categories, many parents do not, owing to the complex nature of parenting children with disabilities and the tensions that characterise parents' feelings and approaches. By categorising parents, we run the risk of applying a binary 'good' or 'bad' parenting in relation to approaches to disability, which is not reflective of complex realities whereby parents may move back and forth between these 'types' or migrate from one to another. Instead, I propose that thinking about parents' actions at the individual level through the lens of microactivist performances is a more nuanced approach as it helps us unpack those tensions and brings forth the possibility that parents can be simultaneously allied, professional and governed in different combinations and at varying moments.

To summarise, the struggle to build habitable worlds (Garland-Thompson, 2015) can be engaged in *by* people with disabilities themselves or by other people. Dokumaci terms this *people as affordances*, by improvising creative solutions to inaccessibility that constitute repeated and ongoing 'performances' (2020). Whilst in Dokumaci's work (ibid), this was mainly applied to home-based scenarios of physical care acts, based on the experiences of people with arthritis, I aim to demonstrate how applying the concept to other 'non-physical' care and advocacy actions can be helpful. I suggest that using the framing of *people as affordances* aids recognition of how mother-carers engage in *struggle*, or everyday *microactivist performances* (Dokumaci, 2020) to create a more just world for themselves and their children and to survive in a context of chronic denial of rights or 'shrunken' affordances and debility (Dokumaci, 2023; Puar, 2017; Williamson et al., 2023). From this perspective, through repeated and varied microactivist 'performances', mothers repeatedly create temporary or permanent affordances to allow their children access to systems, services and in some cases, essential life-saving medicines or treatments. Applying the lens of 'microactivism' therefore helps illuminate the political nature of maternal actions on behalf of children with disabilities to ensure their survival in an environment of shrunken

affordances; actions that might otherwise be depoliticised and obscured as merely part of mothers' roles or considered trivial and inconsequential.

In this chapter, I propose three different types of microactivist performances (Dokumaci, 2020) identified in participants' accounts that mothers engage in as individuals, including world-(re)imagining, self-education and fighting the system. Whilst they are presented separately for precise analysis, I acknowledge that these types of performances are often intertwined and complex, influencing and reliant on one another. For example, world-(re)imagining was linked to self-education, both prerequisites to fighting the system. However, I also reaffirm the ongoing nature of microactivist performances and that they are repeated, evolving and continuous (Dokumaci, 2019).

6.2.1. World-(re)imagining

Dokumaci writes about building habitable worlds, environments that welcome and cater for people with disabilities (Garland-Thompson, 2015), through affordance creation (2019, 2023). Drawing on the work of critical disability scholars who have used framings of reimagining (Kafer, 2013; McLaughlin et al., 2008; Rapp & Ginsburg, 2011; Singh, 2016), I suggest that to build new disability worlds, one must first be able to reimagine the future to be built. I, therefore, refer to this as world-(re)imagining, to stress that this process is aligned to the paradigm shift (Rapp & Ginsburg, 2011) that often happens in mothers of children with disabilities, as explored in Chapter Five. However, there are different ways to interpret this world-(re)imagining and its motivations. So I outline here two possibilities that I will use to analyse the world-(re)imagining that I suggest occurs before mothers' microactivist performances, also discussed in this section.

The first interpretation of world-(re)imagining is that the 'struggle' was part of the engagement in scientific motherhood, as Frederick (2017) proposed, through the partnership with medical professionals to engineer a 'normal' child, for which mothers are held responsible. This understanding reflects the professional and governed parent 'types' outlined in the previous subsection (McLaughlin et al., 2008). In this instance, the aim of the 'struggle' was, therefore, towards accessing healthcare services to correct or minimise the impacts of their child's disability, as described in the previous chapter, where some parents exhibited cure-seeking behaviour through partnership with healthcare professionals. The (re)imagining could therefore see a world of possibility in cure or normalisation.

We are reminded here that linear narratives of development based on individual and biomedical framings of disability can interfere with positive narratives of disability (Fischer & Goodley, 2007). This was demonstrated in the previous chapter, whereby some parents struggled to reconcile their child's diagnosis or disability discovery. The world-building in this

case was prefaced by imagining alternative futures whereby they imagined their children would be ‘more normal’ or their functioning could be less restricted by their impairment. I do not, however, mean to downplay the necessity of medical intervention for many children, nor to confuse mothers’ desires for their children’s health and wellbeing with a desire for normalisation, yet, at times, boundaries are blurred. Therefore, some of the microactivist performances to be presented in this chapter are more closely aligned, at times, with the rejection of difference through normalisation processes.

The second interpretation is that ‘struggle’ could be viewed as resisting the ‘normalcy project’ (Frederick, 2017), through mothers’ rejection of societal norms that *other* their children and the governance of motherhood, reflecting the allied parent type (McLaughlin et al., 2008). Indeed, research on parent disability activism over time suggests that *'increasingly…parents are questioning and challenging the concept of "normal" itself*' (Green, Darling, & Wilbers, 2013, p. 1). This indicates that parents have been influenced by society's changing approaches to the concept of disability, which departs from biomedical understandings and increasingly resists scientific motherhood (Frederick, 2017). That said, since Green’s work is mainly based on a review of Western literature, it is difficult to know how far this applies to the study context.

Drawing on the work of Paulo Freire (1970), I suggest here that for mothers to engage in struggle against the normalcy project, they must first develop consciousness of the injustice that they and their children are facing and their own role in the perpetuation of this, or something which I will discuss as critiquing normality. As part of this ongoing process, they also imagine alternative futures where their children are not devalued and excluded for being ‘abnormal’ and also engage in ‘new kinship imaginaries’ (Rapp & Ginsburg, 2011), that reimagine the future relationships they have with their children along non-normative trajectories. I reaffirm here that rather than these approaches to ‘struggle’ being a binary – either a promulgation or rejection of the normalcy project governed by scientific motherhood (Frederick, 2017), mothers can and often do simultaneously engage *in* and *reject* the normalcy project through their struggles. As such, they cannot always be neatly categorised as one type of parent. I will next present these two key features of imagined world-building identified through the data that have already been touched on: alternative futures and critiquing normality.

A. Alternative futures

As noted, a key part of mothers' everyday struggles was rooted in the imagining of an alternative future for themselves and their children. It may be helpful to consider the work of scholars who theorise futurity, in thinking about how imagining alternative futures links to current actions of those located in sites of oppression. Laura Jaffee (2018) writes, 'How we imagine that future, has significant implications for the efficacy of present-day struggles toward decolonial disability justice' (2018, p. 1419). This reflection is particularly relevant in the postcolonial context of Brazil, where the struggle and need to imagine alternative futures is not merely a case of getting the best quality of life but is integral to survival in a context of extreme violence and oppression, something especially experienced by the Black and indigenous populations. Kevin Blanks (2024) further presents the idea of black alterlivability or black worldmaking, rooted in Aimi Hamraie's (2020) concept of alterlivability - a design philosophy that centres marginalised subjects. In the same way that Kafer and Dokumaci refer to the reimagining of present and future for disabled bodies, Blanks describes how black queer disabled people 'invent new grammars to address the violence of systemic oppression' (2024, p. 137) by imagining new and liveable futures and grammars needed for the survival of black bodies.

Black mothers of Black children with disabilities, therefore, must engage in alternative future building through imagining and acting for a world that does not endanger the lives of Black people nor people with disabilities. For example, mother 6.3 in São Paulo described how *'you need to build a minimally welcoming country so that he does not later become a victim of a violent police…a 1% 2% chance of surviving when you're not here.'* Through her struggle for the future survival of her Black Autistic son, she speaks in terms of the broader collective struggle for an alternative future Brazil in which Black boys and men are not subjected to police violence. Indeed, without imagining a future where the survival and thriving of Black and disabled communities are possible, the motivation for present-day struggles would have no compass. What is not possible to resolve through this study is how far the future imaginings of Brazilian mothers for their children with disabilities align with those of adult disability activists or the children themselves. This is a potential site of exploration for future research.

As reported in the previous chapter, denial and difficulty in acceptance following a diagnosis or disability discovery could lead to cure-seeking actions. I note here that pursuing therapies, a vast category covering many types of medical and therapeutic intervention, did not always seek to necessarily 'normalise' children, and in many cases, is justified and necessary. However, there were other instances in which this was linked to imagining an alternative future where their child displayed more 'normal behaviours' for their age. This is perhaps related to themes of denial of the child's disability and a reality that did not match with their imagined child, as explored in the previous chapter. For example, the social

worker interviewed in São Paulo reported parents who sought intensive treatment via therapies for children who were Autistic or had intellectual disabilities, making comments, such as, '"*But he'll learn, he's not talking, but I read on Google that he'll be talking soon"'.* These comments indicated that the parents' actions were linked to the imagined future realities of a child developing along 'normal' trajectories of oral communication. I do not aim to judge mothers on their actions here, but point out the links between different and sometimes conflicting parents' actions linked to imagined alternative futures, especially during the adjustment period.

As highlighted earlier, I also propose that the different approaches to imagining alternative futures, although sitting in tension with each other, could sometimes be simultaneous features of mothers' actions. Whilst navigating negative experiences of systems of oppression both for themselves and their children, mothers of children with disabilities use the new understandings they have obtained about the world through their own experiences as well as the external pressures of the regulation of motherhood to implement 'the normalcy project' (Frederick, 2017), as a means of engaging in the reimagining of alternative futures. I argue that to engage in world building through ongoing microactivist performances (Dokumaci, 2020), mothers first must engage in world-(re)imagining to provide a blueprint for the building process and have self-efficacy, belief in their capacity to enact change. It is assumed that to reimagine alternative futures of the social environment, mothers must first reach a point of acceptance or adjustment to their child's disability. Imagining alternative futures is therefore part of the preceding stage to mothers' individual and collective actions and can also be viewed as a microactivist performance.

B. Critiquing 'normality'

Across research sites, 'struggle' could be linked to how mothers' experiences of parenting a child with a disability led to what Rapp and Ginsburg (2011) call a paradigm shift in the way that they saw the world. Most mothers and mother-leaders did not name negative experiences as ableism [*PT: capacitismo*], *per se,* since, as a relatively new term in Brazil they were more likely to describe negative experiences as prejudice [PT: preconceito], as denial [PT: negação] or lack of rights, or through metaphors such as '*few open doors'* [no ID, Rio de Janeiro]. For some, the recognition of these experiences had led to a radical shift in how they viewed and dealt with the world and the '*deconstruction of rights and wrongs*' [anonymous mother, Bahia]. Whilst it was difficult to know to what extent these views were shared, mothers across all research sites and with children with varying disabilities reported realising how disability stereotypes, negative attitudes and the design of systems limited their children. As described by mother 2.3 in Bahia, this led to recognition that,

> *'We can go further. We can make them grow, we can make them evolve…It's not possible that he has the BPC just to stay indoors, just eating and surviving. He is not a tree… I was able to notice it…in my son and I know that many other mothers also, within their homes, notice the capacity that their children have to grow and evolve. But the system wants to keep you dumb.'*

Mothers who had developed this critical view had individual struggles that were ultimately rooted in an assertion that their children were fully human, capable of 'evolving and growing'. I offer that this means recognition of their child's individual potential, even if their development did not fit with the expectations of 'normality' as prescribed by society.

Like disability activists who use embodied knowledge of disability to disrupt dominant disability framings (Orsini, 2009), mothers can also demonstrate similar critical approaches to biomedical framings, questioning the concept of normality based on their own embodied experience of parenting a child with a disability. During the group presentations in Bahia, one group in particular critiqued dominant medicalised or individualised narratives of disability, seen as '*the standard that society imposes on us'* [Mother 3.1, Bahia]. Interestingly, the group recognised this as a standard used by society to judge not only their children but also themselves as women and mothers. As the presenter-mother put it, '*when I say* "we" *it's because we are too, we don't just say our children, we say us too. So, because we don't follow the standard, we [mothers] are seen as different beings.'* In this way, some mothers recognised and voiced their own embodied knowledge that was simultaneously separate but also linked to their children's experiences. This might be seen as both a critique and recognition of the links between the normalcy project and the demands of 'perfect motherhood', whereby mothers are subjected to display normalcy, health, heteronormativity, a nuclear family and middle-classness (and, I add, whiteness), suggested by Frederick (2017). Mothers saw their experiences as shaped by society's ideals of normality and perfection in contrast to a motherhood and childhood that was outside of the norm.

For some mothers in the study, conscious realisations about disability discrimination and the subjectivity of 'normality' derived from their experiences of oppression defined the approach to their own 'struggle'. I see this as an indication of what Douglas et al. (2017, p.17) term crip care pedagogies and practices, an approach that '(re)orients those in care relationships…as relationally constitutive learners/teachers who generate knowledge through approaching the care exchange as a teaching and learning encounter.' Through the experience of mothering their children with disabilities, these mothers had come to learn to look at the world, their children and their relationships with them, in different ways that revealed systems of oppression that were previously invisible to them.

However, despite these realisations, mothers referring to themselves as 'activists' was rare. I draw here on the work of Ryan and Runswick-Cole (2009), who disagree with Searle-Chatterjee's (1999) definition to suggest that self-identification is not an essential requirement for activism. I suggest that, since activism is typically understood as systemic, mothers can develop an activist stance and engage in activist activities without outwardly identifying as such, especially if their actions remain on the individual or peer level. Morrison et al. in their study of parent activism in New Zealand, observed how parents' 'daily hammering against normative notions of disability' (2022, p. 129) uses up the time and energy that they might have to engage in larger acts of resistance. I suggest here that larger acts of resistance are more likely to be defined as 'activism' than the daily hammerings, or small acts, that take up most of parents' time yet remain invisible. I add here that mothers' lack of activist self-identification is down to a depoliticisation of the additional everyday struggles of mothers of children with disabilities, disempowerment, and invisibilisation of microactivist performances. This is something which I will expand on in the following sections.

Furthermore, in the case of mothers of children with disabilities, 'ownership' of or proximity to the issue can influence identification with the cause. For some mothers, their personal experiences had motivated them to 'take up the struggle' of people with disabilities, something that they had previously thought of as irrelevant or separate from their lives. For example, mother 5.3 in Rio de Janeiro commented how, through the experience of becoming a full-time carer for her daughter and giving up work, she changed her view about her role in the struggle for disability rights. She reflected, *'I can fight for a cause, which I often neglected, thinking that the struggle would not be mine... disability is not just for the person who is diagnosed, but for all those others who do not have it.'* For many mothers, the struggle had not been a conscious choice but one borne of necessity for the well-being of their child and a loss of prior identity. This lack of conscious choice might explain the identification as aligned with 'the cause' but not explicit identification as an activist.

According to Panitch (2008), activism is essential for advancing the rights of children with disabilities, but also as a way for mothers to assert their identity in opposition to traditional gender roles and to liberate themselves from marginalisation. Recognising that their current experiences and norms were not the only reality to accept, was a key motivation for mother 2.3 in Bahia to engage in the struggle. She spoke about her resistance to *'no information, no knowledge'* and how she resisted this 'submission' to accept the limitations placed on her son by the system.

> *'It's the same with the husband. Do you understand? Submissive. So that you only accept what is imposed. And I understood that this is another uprising, it's another moment of "Look, no, I don't accept it, I don't want it. It won't be like that anymore. Let me understand that this could be different.'*

By comparing submission to 'the system' to submission to a husband, she is drawing links between her individual struggles within the home to the battle against the wider expectations placed on her as a woman and mother within a patriarchal society. This assertion of mothers' individual identities and power to resist stereotypes for both them and their children by imagining alternative futures, i.e. *'how this could be different',* was key to world-(re)imagining as part of the microactivist performances that made up mothers' everyday 'struggles'.

6.2.2. Self-education

As suggested in the previous chapter, mothers commonly experience anomie, or feelings of powerlessness, following the birth or diagnosis of their child owing to the extreme lack of knowledge they had and the lack of assistance from professionals (Green et al., 2013). Throughout the project, mothers reflected upon the role of self-education, including embodied knowledge-acquisition, to resist the state's failures to provide the necessary information and support that contributed to anomie. This reflection is particularly relevant because, according to Wright and Taylor (2014), the self-education process of parents relates to how effective individual advocacy is across all settings. They also highlight how the process features in how some parents engage in education of professionals and the wider public as part of macro-level advocacy or activism. Self-education was therefore seen by many mothers as a necessary part of their struggle to navigate following being '*parachuted into this world of disability'* [mother 5.1, Rio de Janeiro] – a world that had been unknown to them before having their child or receiving a diagnosis. Education across a broad range of areas was therefore seen as essential, as summarised by one mother [no ID] during the group presentations in Bahia,

> *'when the mother discovers that she is the mother of an autistic person, she automatically becomes a lawyer, because she discovers rights that she didn't even know existed. She discovers medicine because she has to have… a library of various medicines… And she also sees herself as a social worker [to support other mothers].'*

The implication here is that professional-level knowledge and skills are an expected and necessary part of the struggle of being a mother of a child with a disability to be able to compete with or contest the 'expert' knowledge of professionals within these systems. Frederick names this 'scientific motherhood', whereby mothers are responsibilised for engineering a 'normal' child as (part of the 'normalcy project') through the dedicated application of scientific and medical knowledge and partnership with professionals (2017). It can, therefore, be viewed as integral to the professional parent role (McLaughlin et al.,

2008) as parents use high-level medical knowledge to support and/or dispute dominant biomedical knowledge to advocate for their child (Fitzgerald, 2008).

Active self-education and embodied knowledge acquired through experience allowed mothers to become experts themselves, rebalancing the unequal power dynamics of knowledge between mothers and professionals working in 'the system'. It also created the conditions to be able to access those systems in the absence of sufficient support, as noted in the previous chapter. Embodied knowledge, developed through the experience of mothering, could also be practical skills necessary to deal with the daily realities of a child with complex needs (for example, feeding, positioning, administering therapies or medication) and ensure the child's survival, wellbeing or ability to 'grow and evolve', as outlined earlier.

Active self-education was often accessed online and through social media, which provides unlimited information. For example, one mother in Bahia had actively sought out information and courses online about disability history and ableism, '*about the history of the struggle of people with disabilities…I learned how to fight for the rights of people with disabilities… the correct way to look at people with disabilities, not with that look of pity'*[mother leader, Bahia]. I note here that the self-education of this mother using knowledge from Autistic and disability self-advocates was also motivated by her own identity as a woman with a disability. However, this did not apply to most of the other mothers. Whilst most spoke about knowledge they had gained in specific professional areas like those listed above, there were limited reports of other mothers being exposed to or seeking to learn about disability history or specifically anti-ableism from the perspective of adults with disabilities. I observe that, generally, mothers were likely to seek out alternative knowledge from other parent activists and 'expert' knowledge to challenge professionals or more easily navigate systems. This is significant because it indicates either a lack of exposure and access to such information or a lack of willingness to engage in such forms of knowledge. Types of knowledge will be explored in detail later in the chapter.

Self-education was also viewed by some as an act of resistance in itself, especially in relation to mothers' peripheral identities, which they saw as stigmatised at the same time as providing a unique position for action. For example, mother 5.1 in Rio de Janeiro spoke about how her experiences of growing up in a favela had influenced her decision to complete higher education because *'unfortunately, in our society they say that people living in favelas have no right to anything, nothing comes out of there.'* For her, as well as becoming living proof that this stereotype was false, she felt that this education would help her in *'bringing this world of possibilities of help and support'* back to the community where she had grown up. We can see here how mothers' acts of self-education could be linked to resistance to societal discrimination based on peripheral identity as well as motivation to engage in systems-level activism, which will be discussed further in the following chapter.

However, education as resistance is not a strategy that can be or is engaged in by all mothers. Mothers of children with Congenital Zika Syndrome (CZS) often face significant barriers to engaging in educational activities due to the compounded challenges of caregiving, financial strain, and systemic inequalities. Mother leader 5 in Minas Gerais noted that many mothers in her network were too exhausted to participate in educational and research initiatives she attempted to organise, including this study; '*they are really tired. The right word is this*.' Whilst this does not mean that these mothers did not intentionally engage in other forms of self-education, it highlights that exhaustion and stress caused by continuous advocacy and care for children with disabilities is a barrier, as reported across various studies (Green et al., 2013; Kuper et al., 2019; Masefield et al., 2020). This is probably a factor that interferes with caregivers' ability to engage in education, alongside the fact that most of them were single mothers and solo carers.

Similarly, the socioeconomic situation and pre-motherhood educational levels may also be relevant. For example, previous research in Brazil found that the low socioeconomic background of mothers of children with CZS impacted the time and means available to educate themselves about support services (Centre for Reproductive Rights, 2018). In the last chapter, restricted access to the internet, literacy and digital illiteracy were noted as barriers to access to information. It is clear from the reflections included in this chapter that this barrier has impeded the ability of certain mothers to engage in self-education using the vast sea of information available on the internet and social media. In the next section, I consider how mothers utilise the knowledge they acquire in fighting the system.

6.2.3. Fighting the system

In the previous chapter, I presented an overview of access to information and key services in peripheral areas and how these shaped mothers' experiences, through the lens of *shrunken affordances*. I now focus on the types of actions mothers were engaged in as part of their everyday individual 'struggle' within this context. I suggest that mothers' experiences of 'struggle' demonstrate what Dokumaci (2019) frames within her theory of microactivist affordances as repeated, ongoing, creative and improvised 'performances' that build new habitable worlds for people with disabilities (Garland-Thompson, 2015). In a context of shrunken affordances, such as the periphery, whereby access to services is severely restricted, these microactivist performances can often be the only way access can be achieved. During the conversation circles, mothers discussed their actions to get their children access to health, education or social assistance systems.

Action was often taken in tandem with learning about the systems and the policies and laws governing them, as outlined in the previous section. However, these actions were often

improvised, especially when mothers did not know where or how to start. For example, two mothers in Bahia noted separately, that having been denied places for therapies at their local Reference Centres for Social Assistance (*Centro de Referência da Assistência Social (CRAS))* they had begun physically '*knocking on doors'* of other reference centres and service providers in the area to try and get a place for their child. Framing the context of low availability of places for therapies in the local areas as shrinking affordances within the environment, knocking on doors constitutes a pragmatic, microactivist, improvised and *site-specific performance* (ibid) – that aims to adapt to the circumstance of shrunken affordances by building or opening a new affordance in the form of a therapy place.

Mothers mentioned 'making a scene' [*PT: fazer barraco*] and 'quarrelling' [*PT: brigar*] as necessary actions in fighting the system that we can analyse as affordance-creating 'performances' (Dokumaci, 2019). A mother in Bahia noted that to get access to necessary support in school, '*you have to go in, go to the Education Department and make a fuss.*' However, people's reactions to mothers asserting their rights by making a scene could invoke racist stereotypes about Black women as 'barraqueiras' [*Eng: trouble-makers*]. Mother leader 4 in Rio de Janeiro reflected how asserting her rights could be seen by others as '*abusive'*, whilst recounting a story where she refused to leave a clinic where her son's neurologist had failed to show up to work because of a broken-down car, after she had spent two hours travelling on public transport with her son to get there. As articulated by another mother 1.2 in Bahia, *'they say that we are troublemakers...that we are rude…I like to tell people that this is prejudice, it is racism.'* The act of 'making a fuss' was a microactivist performance that mothers noted led to success in getting access to services and rights that would otherwise not be guaranteed. However, it also came at the cost to mothers, and particularly Black mothers, of being subjected to racist and sexist stereotypes that intended to delegitimise their actions, oppress and inflict harm.

Microactivist performances of mothers were often ongoing and varied, with specific actions depending on the context, location, and system. This observation helps to reveal the discretionary nature of Brazilian systems, where resource scarcity, informality, and the discretion of workers are key features that define access (da Silva & Moreira, 2021; Nunes & Lotta, 2019). These features mean that microactivist performances are even more necessary because systems cannot be guaranteed to run as intended. Performances may be informal and improvised, as described above, or take place within formal, bureaucratic mechanisms. Many of the mothers' actions were rooted in bureaucratic processes that relied on paperwork, and many mothers explained how they kept having to 'run after' [*PT: correr atrás*] various professionals to get to the next step in their ongoing struggle within a Kafkaesque bureaucratic process. As a mother in São Paulo noted, '*I kept complaining and fighting, running after the doctor and the others to ask for a detailed report of the therapies.'*

Constantly having to 'run after' professionals for paperwork was seen as a necessary part of the individual struggle of mothers and formed an essential part of fighting the system. In some cases, bureaucratic struggles across different systems took place simultaneously. This is exemplified by the case of mother 7.1 in São Paulo, who spent over a year fighting for health insurance companies to pay for an expensive diagnostic test (that was not provided on the SUS) to get her daughter's rare genetic condition diagnosed so that she could get access to the correct medical and therapeutic treatments.

> *'So we spent practically a year waiting to take this [diagnostic] exam... I had to file a complaint against the private health plan [provider], keep calling…that sort of fight. Until I got tired. Then I stopped, hung up, and was trying to get another [health insurance] agreement…then I started my work and waited, until one day when I received the call that it had been approved, and I just made an appointment and took it. All these years [then] it takes three months just to get [the exam] results.'*

The mother above described how, despite preferring to be the primary caregiver for her daughter, she had given up full-time custody to the child's father and got a job to pay for private health insurance, *so she doesn't miss any...[of] the therapy she's undergoing.'* These ongoing and indirect actions of world-building, involving knocking on doors, running after paperwork and giving up direct caring responsibilities to work, would not be recognised as disability activism in another context. However, by defining activism 'not by who engages in it, where and how, but by what activism does and what it affords' (Dokumaci, 2019, p. 516), we make visible what mothers' everyday and ongoing microactivism *affords* their children – a diagnosis, a place in therapy, health insurance coverage.

Turning to the legal system was a feature of some mothers' experiences, as they attempted to guarantee access to healthcare, education and relevant benefits such as the BPC and child support to which they had initially been denied. As noted in Chapter Five, the steady increase in judicialisation of the BPC indicates an alarming trend towards disability laws and policies only being implemented after the judicial process results in a court order. Using the legal system did not always guarantee access to benefits, as mother 7.2 in Rio de Janeiro shared: '*you have to fight. I had to go to court to get the [child support] pension,[but] it's still missing.'*

In another instance, a mother in São Paulo had been forced to consider taking legal action when her health insurance plan refused to cover an expensive and lifesaving heart medication for her son. Exploring various avenues simultaneously, she had managed to get the health insurance company to pay eventually using its complaint mechanism, but only after footing the bill herself in the interim. Relying on the system alone to provide access would likely have resulted in his death, and so paying herself was a necessary action whilst she explored other affordances to his medication, including formal complaint and legal

mechanisms. I include this under the definition of microactivist performances to illustrate how using the legal system was spoken about as an everyday and expected action of a mother of a child with a disability. Again, I point here to the invisible acts of these mothers that go beyond the typical expectations of motherhood, yet are still somehow trivialised as part of the mothering role.

As observed in the previous chapter, often people who did not qualify for the BPC but also did not have the means to pay for the better quality and fuller coverage via health insurance plans could find themselves in more precarious situations. This is because they were caught between the poor coverage of cheaper health insurance plans and the denial of state assistance on account of a lack or perceived lack of eligibility. In these instances, mothers were forced to adapt and improvise creative solutions, exploring multiple options for creating affordances for their children to access healthcare. This often included switching across private and public healthcare systems, adding their children onto multiple healthcare plans belonging to different family members and investigating various options to guarantee their rights across internal complaint mechanisms and the justice system. As noted earlier, preoccupation with everyday microactivist performances was necessary to secure their children's fundamental rights.

6.3. Chapter summary

In this second and penultimate chapter of analysis, I drew on the contributions of mothers and professionals to analyse the individual-level actions of mothers to create affordances for their children in environments of shrunken affordances. First, this chapter conceptualised the individual actions of mothers as microactivist performances enacted via world re-imagining. The findings revealed that mothers' actions could be linked to their engagement in imagining alternative futures, rooted in resistance to or collusion with the neoliberal 'normalcy project' aiming to cure or normalise difference (Frederick, 2017). Imagined futures were also linked to mothers' embodied knowledge of experiencing and witnessing oppression on the grounds of gender, disability and race.

Secondly, world-(re)imagining could be influenced by mothers' critique of societal ideas of normality, which had resulted in a paradigm shift in how they viewed their child, disability, and the wider world (Rapp & Ginsburg, 2011). I suggested that disability world-(re)imagining is a prerequisite to disability world-building (Dokumaci, 2020), which might be influenced by individuals' exposure to disability narratives and visions of alternative futures, as indicated in the previous chapter. I also presented how mothers individually engage in self-education as a form of microactivism, gathering knowledge that they use to fight systems in a series of microactivist performances (knocking on doors, making a noise, running after people and using the legal system) to create affordances for their children.

I have discussed how mothers' individual-level actions can be viewed as a form of activism by applying the lens of microactivism and seeing mothers as *people as affordances* (Dokumaci, 2020). These microactivist affordances can be seen both as a response to and strategies for navigating a context of shrunken affordances, including daily struggles and denials, as revealed in the previous chapter. Mothers improvise diverse, pragmatic and creative solutions to inaccessibility that constitute repeated and ongoing 'performances' which build new habitable worlds for their children that are not necessarily recognised - neither by themselves nor others - as disability activism nor undertaken by people identifying as disabled themselves (Dokumaci, 2019). By applying a critical disability theory of microactivist affordances to the experiences and actions of mothers of children with disabilities in Brazil, we can challenge understandings of disability activism by questioning who else can be disadvantaged by and resist the shrinking of affordances.

This chapter has sought to demonstrate how considering experiences of mothers and children with disabilities in the periphery calls for greater recognition of the small everyday microactivist performances that mothers engage with on a daily basis, including non-physical acts such as world re-imagining, self-education and fighting the system. In the following chapter, I explore how this can extend to building microactivist networks between mothers engaging in similar microactivist performances and what this means for strategies of collective resistance and empowerment in contexts of extreme oppression.

Chapter 7 – Mothers' Microactivist Networks

7.1. Introduction

In the previous chapter, I looked at mothers' individual struggles and actions. I applied a lens of microactivism, adapted from microactivist affordances (Dokumaci, 2019, 2020) to analyse the small and ongoing 'performances' that mothers take in everyday life to meet the needs of their children in a context of shrunken affordances. Mothers' individual level 'struggle' described additional actions beyond typical 'mothering', including world-(re)imagining, self-education and fighting the system. These microactivist performances (Dokumaci, 2019) are therefore developed as strategies to counteract the lack of information about their rights and used to fight to secure access to services and systems built to exclude them and their children. In this final empirical chapter, I continue this focus but extend Dokumaci's framework beyond the individual and family level to the peer and system level, which Burke et al. define as the different types of parent advocacy (2024).

Applying the theoretical framework that draws on Black feminist and critical scholarship will aid in applying an intersectional analysis that interrogates what disability activism is and who 'does' it. By considering how mothers connect over their struggles and support each other, I develop the concept of microactivist networks, reflecting on how support networks have emerged between mothers of children with disabilities. These networks attempt to counteract the lack of formal support and empower mothers to collectively and individually create and share strategies for affordance creation within environments of shrunken institutional support. I discuss the four key themes that emerged to describe networks' main functions and objectives: emotional support, practical support, knowledge exchange and mediation, negotiation and civic activism.

Later, I introduce a new concept of (macro)activism, which I develop by building on theories of microactivist affordances and people as affordances (Dokumaci, 2019, 2020), to question the relationship between systems-level, peer-level and individual-level activism. This final section explores how, in some cases, microactivist networks have facilitated (macro)activist actions, extending political influence over systems and services through engaging in ad-hoc, targeted campaigns, taking part in dialogical civic engagement and acting as an intermediary between the state and family. This chapter aims to demonstrate that mothers' microactivist networks have developed as essential and, in some cases, influential tools that, as well as providing emotional and practical support to mothers and their children, can also be platforms for activism.

The data presented in this chapter is based on information provided through interviews and conversation circles with mother-leaders from seven mothers' networks – three in Bahia,

two in São Paulo, one in Rio de Janeiro and one in Minas Gerais; and 41 mothers who engaged in conversation circles, the majority of whom were members of one or more mothers' networks. Therefore, this chapter reports on the perspectives of those involved in setting up and running networks and those who have joined them. It aims to demonstrate how mothers of children with disabilities mobilise and structure different types of networks of support between themselves for their empowerment and to address shrunken affordances in peripheral areas.

7.2. Forming, leading and sustaining networks

I define *mothers' networks* here as support networks between mothers, who, in this case, are the primary caregivers of children with disabilities, facilitating peer support, including instrumental, emotional support and knowledge exchange, and in some instances, facilitating collective action towards system change. Whilst also recognising that anyone can provide primary care for children with disabilities, I choose to refer to these networks as *mothers' networks* to highlight the gendered and specifically *maternal* economy of caregiving and advocacy for children with disabilities in Brazil. I also recognise that people who are not mothers or primary caregivers, though more likely to be women family members, also form an essential part of care networks and can engage in mothers' networks. However, the primary focus of this study is on mothers' networks that covered a specific geographic area, often just one or two municipalities.

This subsection focuses on the formation and growth of mothers' networks, including some key characteristics, the aims of networks according to mother leaders and members, mothers' motivations to engage in networks and some insight into issues linked to their sustainability. Six of the seven networks in the study were registered as private associations with legal entity status; the one without was the mothers' network established by a social worker at an APAE centre for children with disabilities in São Paulo. The networks had varying activity levels and formality, with the larger ones regularly employing and paying staff and the smaller ones working on an ad-hoc, voluntary basis, and most activities led by a small group of mother-leaders. I distinguish mother-leaders from other network members in that they established and took on responsibility for growing networks, directing activities and campaigns, sharing information, finding funding and dealing with administrative tasks. In most cases, this work is voluntary. Except for the APAE mothers' network, the other mothers' networks in the study had all been started by one or a small group of mothers, usually between three and five, who shared network responsibilities. I reproduce the table from Chapter Four as a reminder of the networks included in this study.

Network Number	**Network Description**	**State**	**Method of data collection**	**Network description**
Network 1	*Autism*	*Bahia*	*Conversation circle, mother leader interview (1)*	*A network for mothers of Autistic children, founded by a mother with disabilities and other mothers without disabilities. There is no physical space, but meetings are occasionally organised in person. Communication is via WhatsApp and social media.*
Network 2	**Abraço Microcefalia** - *Children with CZS*	*Bahia*	*Mother leader interview (2), visit*	*Network of over 330 families of children with CZS. Physical space with regular events and some services provided, including physiotherapy. Has a website and social media presence.*
Network 3	*Autism*	*Bahia*	*Conversation circle*	*This is a network for families of Autistic people. It has a physical space, regularly runs workshops and events, and provides some services. It communicates via WhatsApp and social media.*
Network 4	**Projeto Marias** - *All disabilities*	*Rio de Janeiro*	*Conversation circle, mother leader interview (4), visit*	*Network of families with children with disabilities. Has a physical space in the Manguinhos complex, regularly runs educational activities for children & parents. Communicate via WhatsApp and social media.*
Network 5	**Anjos de Minas** *Children with CZS*	*Minas Gerais*	*Mother leader interview (5)*	*A network of around 70 mothers of children with CZS. There is no physical space, and the network does not meet regularly owing to distance and issues with accessible public transport. It communicates via WhatsApp and social media.*
Network 6	*Autism*	*São Paulo*	*Conversation circle, mother*	*A network of parents of Autistic children who have organised to*

			leader interview (6)	*lobby the local government to make changes to the school and health system. The network has no physical space but communicates via WhatsApp and social media.*
Network 7	*All disabilities*	*São Paulo*	*Conversation circle, visit*	*The mothers' group was established at a centre (clinic-school) that served several municipalities. Has a physical space on-site. Runs craft and other workshops and has a bazaar selling second-hand clothes to raise money for the centre.*
Network 8	*All disabilities*	*São Paulo*	*Conversation circle, mother-leader interview (6)*	*A network of parents of children with disabilities that functions via WhatsApp. No physical space or social media presence.*
Network 9	*All disabilities*	*Rio de Janeiro*	*Conversation circle*	*Network of parents of people with disabilities. Has a physical space with a community wardrobe for second-hand items. Communicate via WhatsApp and social media.*
Network 10	*Down Syndrome*	*Rio de Janeiro*	*Conversation circle*	*A network of families who have children with Down syndrome. No physical space, but organise regular events and meet-ups. Communicate via WhatsApp and social media.*

Table 4.1. Mothers' networks

7.2.1. Forming, joining and growing networks - *'fighting alone is difficult, but when you become a collective it becomes easier'*

Mother-leaders described how mothers' networks sometimes formed and grew through chance meetings between mothers who wanted to exchange information and connect with other mothers of young children with disabilities, often in healthcare or educational settings. As mother leader 1 in Bahia described, she '*made friends with a mother at the clinic reception'* where their children both attended therapy sessions *'And then we talked and talked and then we decided to take a walk around Park [X].'* As this indicates, building connections between mothers was also intended to provide emotional support and a sense of belonging for mothers who often felt isolated in their individual 'struggle', and this was often an intention of establishing a network in the first place. Whilst some networks were impairment or diagnosis specific, such as Autism, Zika or Down Syndrome networks, others were more general and included mothers of children with different types of disabilities. In general, networks included in this study were initiated via a conversation between two mothers and then grew through word of mouth, as described by mother 5.3 in Rio de Janeiro,

> *'I found out about [mother's association] from another mother who was part of it. Then she talked to one of the administrators. [name] and [name] contacted me. [Mother's association] was founded by a mother whose son has spina bifida. He is in a wheelchair. And she found it very important to exchange experiences, and the group started with that, as mothers, with children with disabilities, exchanging experiences...Today we are more than 500 families.'*

Similar research on parents of children with disabilities in Brazil also shows that many other parents associations and networks formed when parents of Autistic children and children with multiple or learning disabilities met at clinics or were introduced by physicians during the 1980s (Cavalcante, 2003) and also during and after the Zika epidemic of 2015 and 2016 (Campos et al., 2018; Matos & Silva, 2020). This reveals that healthcare spaces are sites where solidarity and support networks are formed between parents, not only despite but also because of their significance as sites of frustration, exclusion and oppression, as described in Chapter Five. Despite many participants focusing on negative experiences with professionals in the healthcare sector, some mothers noted the support and encouragement of healthcare professionals in forming and growing networks by connecting mothers and advertising networks. I note that these are distinct from peer-to-peer support interventions whereby professionals run networks with their participation, in that professionals tended not to be involved but instead encouraged or enabled their creation by mothers whom they provided formal support to, and perhaps also referred other mothers there.

Besides word of mouth, the internet and social media were essential tools in forming and growing networks, as mothers often turned to the internet for information and support where it was not being provided or accessed through official channels, as outlined in the previous chapter. Mothers also used social media to aid their microactivism, which could often be the catalyst for a network to form. For example, mother leader 6 in São Paulo described how the group formed after another mother '*posted a story on Instagram tagging the city hall and everything, because something had happened to her daughter and it wasn't nice. And her daughter had been through a lot of suffering and she was angry.'* By sharing this story, other mothers and community members helped to share until the post went viral, which resulted in the mother being '*invited by the authorities to talk, to have a chat to try to resolve this issue.'* The emerging digital network resulted in a physical meeting of mothers who usually would not *'talk openly'* about the issues they were facing in their private lives, which further led to the creation of a local mothers' network that fed into a parent advisory group for the municipality with the help of a local councillor. This anecdote highlights the role of the internet and online activism in the formation and growth of networks that engage in collective action, as well as the role of others, for example, local politicians and healthcare workers, in supporting the formation of networks and collective action.

Joining networks was not always limited to affiliation with a specific disability diagnosis, as different networks provided different elements, depending on their objectives and focus. As the mother-leader of the CZS network in Minas Gerais noted, *'it's very common to be part of four, five groups…, I don't see much of a difference, because the groups have atypical mothers, with other pathologies, also with other disabilities.'* Even when groups were diagnosis-specific, the fact that it was common for mothers to be part of specific networks and general networks indicates that identity, whether general or disability specific, was considered fluid rather than static. As a result, mothers sometimes referred to themselves in relation to their child's diagnosis, such as '*Autism mothers*', '*Zika mothers*', but other times more generally, such as '*atypical mothers*' or '*mothers of children with disabilities',* depending on the context in which they were speaking and with whom, and which collective identity they were aligning themselves. As mother 5.1. in Rio de Janeiro put it, '*There are mothers with children with disabilities, autistic, physically disabled and deaf, mute. There we are a group.'* There was therefore recognition beyond individual disability type or network membership of the wider shared experience of mothers, indicating a broader collective identity of mothers of children with disabilities that was perhaps strengthened or facilitated by mothers' networks.

7.2.2. Key characteristics of networks

Mothers-leaders

Mother leaders were a key characteristic of mothers' networks, and all of those included in the study had been formed and sustained by their presence. Project partners and I observed that most networks were created and led by women with comparatively higher socioeconomic status or financial stability than other network members. For example, mother leader 1 in São Paulo recognised that she and other active mothers were in a position of relative privilege in relation to the other mothers in the network. '*Thank God [my son] is well supported, but I am fighting for what yours doesn't have. So, if you look at the mothers who are really active, none of them need it.'* Similarly, mother leader 2 in Bahia had established and run the network for children with CZS, providing services for those in the community despite her own daughter receiving private healthcare on a health plan. Therefore, it is surmised that mothers who did not work or care full-time or who had more practical or financial support were more likely to be involved in establishing and maintaining networks. For three mother leaders across Rio de Janeiro, Bahia and São Paulo, they admitted that they and their children were in comparatively better situations than others in their network, but cited commitment to the collective struggle and being '*worried about those who don't have it'* [Mother leader 1, São Paulo] as a motivator for their leadership. For example, even though her son died during the pandemic, the mother leader 4 in Rio de Janeiro had remained at the project, explaining, *'I am here as a volunteer and I don't even need to be here anymore because I no longer have a sick or disabled child. The project is not mine, it belongs to the community.'*

Digital Networks

From initial conversations between mothers, networks quickly developed a digital presence to enable conversations to continue, usually in the form of WhatsApp groups. Regardless of whether they had access to physical space, all networks had a digital network, making this a key feature of mothers' networks. The primary form of contact between members of digital networks tended to be via WhatsApp groups. Networks had often started as WhatsApp groups and then developed a social media presence, usually a Facebook or Instagram page, which can have between several hundred and several thousand followers. Social media was commonly used for public or private communication between members and information sharing, e.g. about support services or events organised by the network or other organisations. Many networks also used virtual meetings or 'lives' on social media as a cheap and more accessible way to hold meetings and communicate in real time between

members. Online meetings were beneficial for networks that did not have regular access to physical space or for networks where travel for members was difficult due to accessibility, time and financial constraints.

The growth of networks that rely on digital spaces follows the trends in how the internet has revolutionised support networks and activism in recent decades. Digital support networks have provided lifelines for parents of children with disabilities to seek and share social support and information from others with similar lived experiences (Gruebner et al., 2022). We can define social support as including 'emotional support, belonging in a social community, being valued, practical help, and information and guidance' (Drageset, 2021, p.137). Parent networks are therefore essential for those involved in intensive home-based caregiving, who are otherwise debilitated through care work and confinement to the home (Williamson et al., 2023). Furthermore, the internet provides informal political spaces for disability activism that appeal to people intimidated by formal political spaces and therefore widens civic space to enable people to connect the private to the political and turn online spaces into collective action (Trevisan, 2017). This was evident in the case of the São Paulo mother who shared a video online, as mentioned previously. Without digital tools, mothers' ability to connect their personal issues to collective action would be limited by their home-based caring responsibilities. Digital spaces, therefore, play a crucial role in facilitating microactivist networks – connecting mothers engaged in microactivist performances to exchange support and engage in (macro)activism, which will be discussed in further detail later in this chapter.

In-person contact

Whether networks provided opportunities for mothers to meet in person depended on their access to physical space. The geographic and disability-specific nature of groups was due to the focus on access to information about services within a specific geographic area, since the types of services available and the systems to access these could vary across geographic regions and disability type. Although all networks had a digital presence, around two-thirds of those included in the study had access to regular physical space, which they either owned, rented or were given to use for free by other organisations or local councils, either permanently or on an ad-hoc basis. Regularity of in-person meetings depended on how much access to physical space a network had. For example, network 2 for children with CZS in Bahia was provided with free space from the council and had fundraised to offer a free bus for families in the area to travel to the space. However, network 1 for mothers of Autistic children within the same state had not been able to obtain a regular physical space to meet. Within digital networks without access to regular physical space members still might meet in public places, such as parks, to organise in-person events within the community. In-person meetups were used for activities such as providing educational, vocational or recreational activities for children and parents, collecting and distributing

donations or hosting other network activities such as meetings, conversation circles or lectures. Public spaces might be used as in-person gathering points for protests or demonstrations, such as outside the city hall or a bus station.

7.2.3. Sustaining networks

During focus group discussions and interviews, some participants also discussed difficulties sustaining mothers' networks. Whilst this study's goal is to explore how experiences of mothers' links to collective action, this finding is relevant because it gives some insight into barriers to the network's activities due to a drop in participation in or organisation. One reason participants mentioned was the burnout of mother leaders and members. Burnout of informal caregivers is common and a reaction to chronic stress that can lead to emotional exhaustion and a reduced sense of personal achievement (Gérain & Zech, 2019). Burnout was likely a result of a multitude of factors, including intense emotional labour. This is because mothers were sometimes experiencing abuse as well as dealing with their own family and personal struggles, internal network politics, whilst also experiencing discrimination, financial insecurity and other issues that were exacerbated by the COVID-19 pandemic. The mother leader of network 5 in Minas Gerais explained, *'I think it's the "no's" in life, that they, that we take every day, [from] the government, the SUS [national health service]. So, they are really tired. The right word is this.'*

While research on burnout among mothers in peripheral areas involved in disability activism is limited, existing studies highlight high burnout rates among mother-caregivers, activists (Gorski, Lopresti-Goodman, & Rising, 2019), disability activists (Wolbring & Lillywhite, 2023), and racialised individuals experiencing racism burnout (Hawkins, 2021). Through an intersectional lens, mothers caring for disabled children while leading or participating in networks in peripheral areas face compounded pressures, from caregiving and systemic discrimination, which can lead to member and leader burnout, straining the sustainability of these networks. That said, reduced engagement may also stem from other factors, such as internal conflicts, decreased need for support as mothers gain confidence, or reasons beyond this study's scope.

Mother leaders generally cited financial support as a barrier to network formation, growth and sustenance. Most of the networks included in this study were mother-led and self-funded, receiving little or no government assistance to protect against burnout of members or external shocks such as the COVID-19 pandemic. Almost all mother leaders spoke about the financial barriers to sustaining support and advocacy activities. Some had relied on bursaries to provide short-term projects focusing on disability inclusion awareness raising in schools, '*but then the resource ran out, the project ended*' [Mother-leader 2, Bahia]. As mother-leaders worked voluntarily, activities depended on their time and financial stability, either through their personal funding or because they did not need paid employment. While

these networks provide essential support and advocacy, their survival is often precarious due to dependence on mother leaders and the emotional, financial, and practical strains they face, particularly those . Therefore, addressing financial barriers to sustaining mother-led networks and project activities should be a policy priority. The following section will elaborate further on the subjective meanings attached to networks and their work/activities that went beyond but were linked to the stated aims of the networks.

7.3. Connecting the individual to the collective

This section further explores the functions and objectives of the studied mothers' networks through the meanings that mothers and mother leaders attached to them during the conversation circles and interviews. By applying the concept of microactivist networks, I aim to uncover how mothers collectively engage in microactivist performances (Dokumaci, 2020) that create affordances for each other and their children through mothers' networks. Both mother leaders and mother members noted the main objectives of networks as '*support networks*' [PT: rede de apoio]. The findings indicated that support could be categorised in three main ways: emotional support, instrumental support, and knowledge exchange, the first three functions I present. The last function of mothers' networks is facilitating (macro)activism for systems-level change by connecting from the individual level to the collective. I propose that the microactivist actions of these networks in providing support and facilitating (macro)activism aim to create affordances for survival and quality of life in a context of shrunken affordances and debility (Puar, 2017; Williamson et al., 2023). The aims of networks interpreted by mothers and motivations for engagement were explicitly explored during the focus group discussions and interviews with mother leaders. I also triangulated this data with past research and written materials on networks' social media pages and websites.

7.3.1. Emotional support - *'these conversations that we have with each other here strengthen us, lift us up and sustain us'*

Whilst the initial objectives of networks and motivations for engagement varied across networks and individuals, a common objective and function was for networks to provide emotional support by connecting mothers with shared experience. We can understand emotional support as support, care and empathy provided between individuals that offers feelings of love, comfort, security, respect and admiration (Jacobson, 1986) and as a key function of social support. Research on peer support groups for parent-carers in Brazil and other settings also shows that these can provide essential support and improve mental health, wellbeing, coping and empowerment outcomes in the short and longer term (Bray et al., 2017; Duttine et al., 2020; Lancaster et al., 2023b, 2024b). Some mother-leaders cited

emotional support as a key function of networks, and members tended to emphasise the extensive value of the emotional support they received through participating in networks. Therefore, we can see emotional support as an act of microactivism, as it affords survival, well-being, coping and empowerment within a shrunken environment. In this way, mothers' networks are microactivist networks, since they can facilitate emotional support provision, a microactivist act, between members.

During the group presentation activity in Bahia, some groups chose visual and word representations to focus on the meanings and functions of networks (see figure 7.1). This group, during conversation circle 3, justified their choice of the tree metaphor as follows,

> *'We have the root which is the group... we have the trunk that are mothers and children, the supporting trunks….the fruits of what we were able to express…what we found: support network, sisterhood, accessibility, empowerment, visibility, hope, respect, inclusion, love, knowledge.'*

Figure 7.1: *drawing of a tree representing a mother's network during the workshops in Bahia. The words in the tree read: support network, knowledge, love, inclusion, visibility, respect, hope, solidarity, empowerment and accessibility. The word on the left-hand side of the tree reads 'mothers' and on the right-hand side, 'children.'*

As in the Bahia network, other mothers' networks were also described by mothers and mother leaders using family metaphors. This implied that networks were perhaps filling a gap left by absent social support, or even adding a unique type of support that could not be fulfilled by existing social support, such as that from family and professionals. The gendered aspect of these networks may have also contributed to the networks being seen as extended family, especially given the high rates of paternal abandonment within these families and the debilitation that single mothers experienced. For example, mother leader 5 in Minas Gerais explained, '*we say that we are sisters in the struggle.*' The family theme was likely even more accentuated by the fact that half of the online survey participants identified as solo caregivers, with a further third reporting that they received no help from another person in the day-to-day care of their child, as was outlined in the first empirical chapter. Thus, the use of family and tree metaphors presents a picture of the strong relationships and sense of belonging that networks facilitate between members, rooted in shared identities and a shared struggle, especially where their own social support networks and professional networks failed to provide this.

Connectedness

It was understood by mothers and mother leaders that with shared experience came shared language and understanding, an essential part of the emotional support provided between mothers and relieved feelings of isolation in their individual struggles [PT: *luta*]. Mother leader 5 in Minas Gerais explained, *'you only understand a situation until you go through it, right? So we understand each other's language, we answer each other's questions, we consult each other, we help each other because many of these mothers need help.'* She elaborated on how specific knowledge and language around nutrition, medicine, and clothes were a source of common understanding between mothers of children with CZS, for whom specific medical and technical lexicons had become part of everyday life. It is possible that, beyond the link between shared language and informational support, which is to be discussed further in the following section, shared language can also increase feelings of community belonging and decrease feelings of isolation.

For many, the doubts that come with mothering in unknown 'disability' territory and facing barriers to access rights for their children create a lonely and isolating experience. An experience that could be relieved by connecting with others in similar situations. For example, mother 8.1 in São Paulo shared that before joining the mothers' network, '*I had this fear, I had my doubts. Am I failing?…Is it correct? What am I doing?'.* Joining the mothers' network had reduced her feeling of isolation by connecting her with others with the same experiences; *'What I have learned is what I told you that I am not alone. My doubts are the doubts of other mothers. My fears are the fears of other mothers of autistic children.'* Connecting with others had given her a more positive perspective on her own individual struggle and a feeling of belonging. *'When you come across these wonderful*

mothers here, you see that you are on the right path, right? And the welcome they gave me was also wonderful. I am really happy'.

Shared Struggle

Mothers reflected on how engagement with networks led to connecting with shared experiences of other mothers and the validation this brought to their own experiences. Connecting with other mothers who had shared experiences of resisting normative stereotypes for themselves and their children and engaging in microactivist performances helped to further their collective identities as part of a wider struggle. For example, participants described how networks were important to ensure mothers were not alone in their 'struggle' [PT: *luta*], suggesting that knowing the struggles of others seemed to contextualise their own struggle and give them a sense of community. As mother 5.4 put it in Rio de Janeiro, *'the struggle is much bigger than what I'm feeling.'* This indicates that a strong sense of connection between members was facilitated by networks rather than created and directed towards affiliation with the network itself.

Beyond describing a collective identity based on shared experiences, 'struggle' was also used by participants to describe the work of guaranteeing their children's rights. Obtaining rights was seen by many as an aim that became easier to achieve when connected with others via a network. For example, mother leader 4 in Rio de Janeiro explained that *'struggling alone is difficult, but when you become a collective it becomes easier, right? It's easier to guarantee your rights.'* Guaranteeing children's rights was cited widely as an objective of networks across all research sites by mother leaders and network members. Furthermore, the language of rights was frequently used by participants when discussing support networks, with 118 uses of the word *'direito(s)'* [Eng: right(s)] across all the focus group discussions, indicating that this was a key and shared objective. It is noted that the term 'rights' was used by participants both in a general and undefined way, but also in specific relation to the right of children to education and health, which were generally mothers' primary concerns as described in the previous chapter.

Mothers also discussed rights as a collective issue, with recognition that the denial of certain rights was a common feature that united mothers. One mother described her solidarity with the mother leader of a network in Bahia as a duty to help guarantee their children's collective rights.

> *'So, as always, [mother] calls me, I'm with her. There's a struggle, we're here, right? Because I'm here to help. Because we have to come together to help her, because we have to fight for the benefit of our children, for the rights of our children. If we are discriminated against.'*

Therefore, the motivation of individual mothers to join a network was also seen as connected to guaranteeing their children's rights, which networks broadly aimed to achieve.

Preventing crises

The networks were also credited with potentially preventing worsening mental health and severe crises by providing emotional support, especially where formal support was not readily available. Mother leader 5 in Minas Gerais talked about conversations facilitated by the network '*to try to strengthen us'* which, according to her, were particularly important because mothers sometimes feel embarrassed '*to open up about their personal lives'.* She discussed how networks were safe spaces because of other network members' shared experiences and support. During the group presentations from the Bahia workshop, one group described the network as *'a very big fortress'* noting that the exchanges between mothers were strengthening, *'because when we are falling, when we hear what one of our mothers say, we get stronger… these conversations that we have with each other here strengthen us, lift us up and sustain us.'* Mother leader 3 in Bahia described how many mothers of children with disabilities '*are losing heart in this struggle'* and the role of her network was to *'take care of the emotional well-being of these mothers'.*

In more than one research site, mother leaders mentioned the suicides of mothers who had been struggling to get support. Whilst it is unclear to what extent mothers' networks did or could prevent such tragedies, mother leader 1 in Bahia believed the emotional support provided by her own network helped to avoid the suicide of mothers who were unable to access formal support through Psychosocial Care Centres. She described how many mothers '*didn't have access to CAPS [Psychosocial Care Centres]… In places of care that are supposed to welcome these mothers… most of the time they don't.'* She saw the emotional support provided by the network as, *'saving lives…Not only of the mother, but also of that child who will grow up empowered by who he is.'* Research indicates that carers are a high risk group for suicide (T. F. da Costa et al., 2020; O'Dwyer, Andrewartha, & Sansom, 2023), yet there is a severe lack of research on the death and suicide rates of mothers of children with disabilities in Brazil, despite anecdotal evidence which suggests that rates are high (Ayub, 2022), which is linked to the lack of support systems in place for both people with disabilities and caregivers. This study showed that networks created safe spaces for mothers to express their emotions and share and receive support, which was particularly vital as a preventative measure when access to formal support services was scarce.

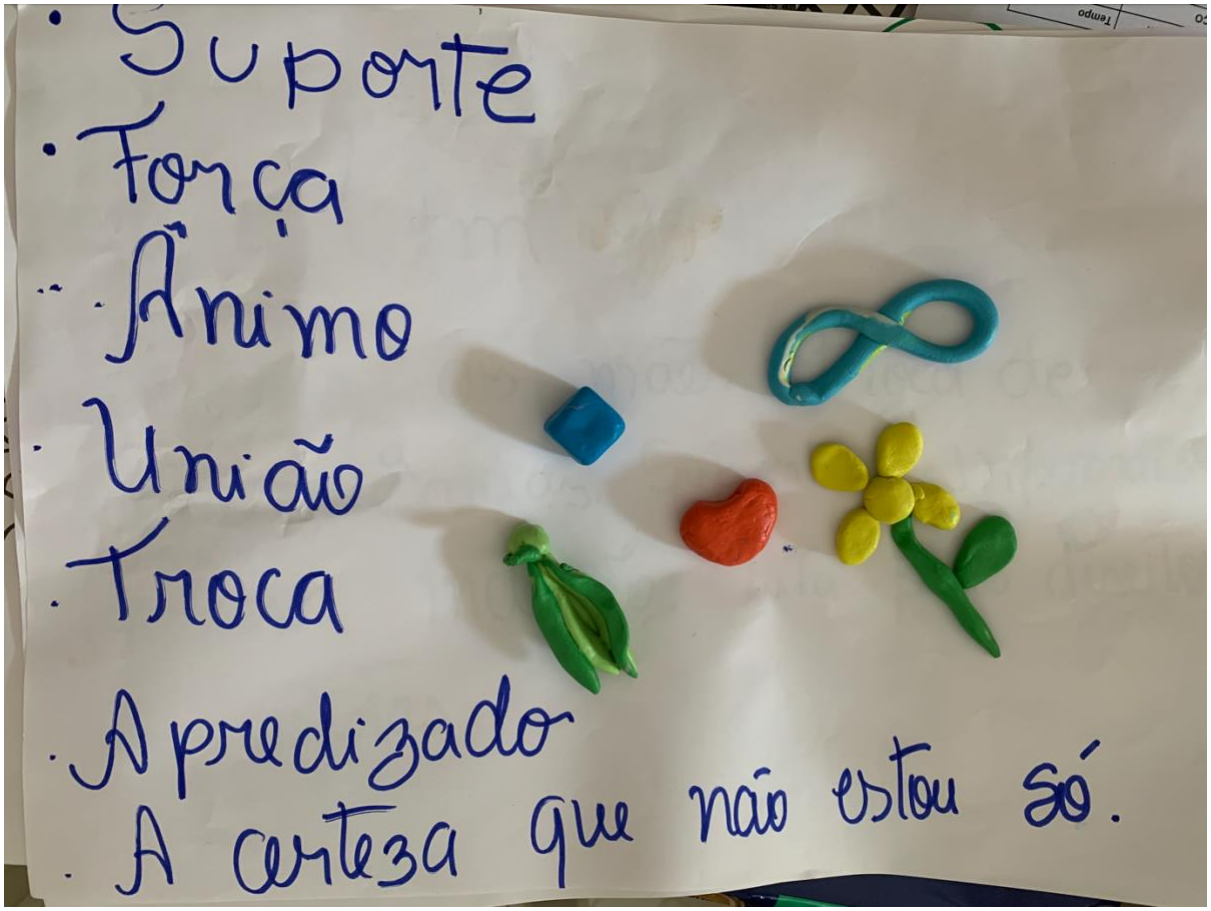


Figure 7.2: *words and images made in coloured plasticine during the workshop in Bahia. The words read: support, strength, encouragement, union, exchange, learning, the certainty that I am not alone. The images made in plasticine include a neurodiversity infinity symbol, a flower, a heart, a square and some leaves.*

For some mothers, the virtual support that mothers' networks provided via social media and messaging groups was an important source of real-time emotional support. Mother 5.3 in Rio de Janeiro described how people joined the WhatsApp group she was part of and the regular, everyday exchanges that took place in the group that relied on shared understanding and empathy, stating, *'something happens to the child at school or in the hospital and…we're going to get it off our chest'.* She described how this is the network's primary function and emphasised the importance of the emotional support it provides her personally. *'[Network], for me, was very fundamental. It's my whole, whole, whole network.'* Despite this network being a hybrid network with access to physical space and providing mutual aid, the meanings she attaches to the function of emotional support that this provides her at any time of day show the significance of virtual support networks. Recent research on online peer support for mothers of young children shows that mothers are increasingly turning to the internet for emotional support, information and community building and belonging (Drentea & Moren-Cross, 2005; Yamashita, Isumi, & Fujiwara, 2022). Similarly, parents of children with disabilities use health-related digital platforms, such as

social media, forums and specific health websites, to seek and share social support and information from others with similar lived experiences (Gruebner et al., 2022).

Feeling emotionally supported via connections with other mothers helped to combat some of the stress associated with a lack of access within a context of shrunken affordances. Connecting with others with lived experiences afforded understanding of their own experiences and provided a sense of community. Interestingly, the social support literature indicates that perceived support is more important than received support in relation to better mental health and quality of life (Da Costa et al, 2023; Dragaset, 2021; Uchino, 2009; Sarason & Sarason, 1990). Being connected to other members does not necessarily create affordances in the environment. However, it is possible that being a member of a mothers' network affords mothers perceived support through the emotional support and exchanges that occur, or by being able to connect with and be listened to by others who 'get it'.

7.3.2. Instrumental support - *'everyone comes together and gives what they can to help'*

Although largely framed by mothers as secondary to emotional support, mothers and mother-leaders listed one of the other key functions of mothers' networks as providing practical assistance. Practical assistance included extensive assistance types, including facilitating access to a wide range of services, such as physiotherapy, social assistance, mental health support or extra-curricular education programmes or facilitating mutual aid between members. Therefore, we can consider this a form of instrumental support, defined as practical assistance to meet needs, such as financial assistance, providing services, or another form of physical help that can help reduce stress during adversity (Cohen & Wills, 1985). The link between reducing stress and providing instrumental support is key to consider within a context of shrunken affordances.

This indicates that these things were often interdependent, facilitated by networks out of necessity to meet the basic needs of members facing extreme hardship. Generally, instrumental support seen in this study took two forms; firstly, facilitation of mutual aid through goods and financial assistance, either through donations from charities and businesses or sharing of goods and economic resources between members of networks. Secondly, through the facilitation and provision of free or discounted services, usually in education, healthcare and social services. The extent and ways in which instrumental support was provided by the networks included in the study varied depending on their level of informality, links and support from other organisations facilitated by mother-leaders, the needs of members, and the beliefs of mother-leaders.

Some mothers' networks more explicitly aimed to provide instrumental support, which was seen as firmly linked to the health and well-being of mothers and children, especially when families were faced with complex issues relating to the child's disability and information and services were lacking. For example, instrumental support had been the key objective of the establishment of the network of mothers of children with CZS in Bahia, which mother-leader 2 saw as '*essential to be able to educate, deal with the child, with microcephaly… congenital Zika virus syndrome*'. She explained how, '*at the beginning, we focused a lot on the children. Rehabilitation, rehabilitation*.' This is supported by previous CZS research, highlighting the importance of mothers' networks in the collective care of children (Lustosa & Alves, 2019; Pinheiro, 2018). In this case, the network facilitated access to therapies, which for some was a key instrumental support in the local area, as specialist therapies were not always available without travelling long distances. However, whilst instrumental support had been the network's primary objective initially, she explained how '*now we are at a time when we are thinking more about the mothers. We are holding discussion groups, providing psychological care, doing this type of self-care, strengthening, empowerment work*.' This indicates that whilst instrumental support was an initial objective of the network to meet the immediate need of families, this network was beginning to recognise the importance of networks also providing emotional support for mothers.

Facilitating access to *cesta básica* [EN: basic support baskets], for example, was seen by mother-leader 4 in Rio de Janeiro as a secondary objective to other types of instrumental support her network provided that focused on education, self-empowerment and navigation of existing government support systems. She insisted that *'we deliver basic support baskets, but that's a detail. We are not a welfare project.'* Her justification was that informal support was secondary to formal support from the government. *'I say, the government's social services work. If you don't go there, there's no point in coming to me...First, look there, then you can come to me.'* In comparison, she saw informal support as precarious and *'just a support, I don't even know how long - There it's forever, here it's temporary…we get in the Support Basket, but tomorrow we may not get in anymore, then what? Are you only here because of the Support Basket? No, you are here because we are a collective and we need to strengthen ourselves.'* As indicated, supporting and facilitating the self-reliance of families was the main aim of this network, with instrumental support being seen as just a component of the process or 'detail'. This observation that certain forms of instrumental support are seen as '*a detail'* indicates that it was sometimes a necessary function of networks to ensure that members had their fundamental needs met, in circumstances where the state did not guarantee these. At the same time, they were wary of creating reliance amongst members and undermining the state's responsibility to provide for its citizens.

Instrumental support could also consist of mutual aid, which differs from donations in that it is a horizontal support structure between members that could include pooling financial or

practical resources to facilitate activities or help members in need. For example, mother 5.3, a member of a different network in Rio de Janeiro, described how their members pooled finances to rent a space used to collect and distribute donations to a 'solidarity wardrobe'. She explained, *'we ask, the girls ask for help from families to donate five, six, seven, 10 R$, whatever amount is enough to provide space…a place where we can support the donation.'* Financial donations were also collected on an ad-hoc basis to support members struggling financially to cover their basic costs. *'A mother is in need of gas. So, she puts it in a group, then everyone comes together and gives what they can to help, that's it. That's how it goes.'* The collective and horizontal nature of mutual aid that is demonstrated in this example shows that mutual aid could be a form of collective instrumental support facilitated by networks. I observe that instrumental support is a key objective and essential function of many networks. However, it remains a secondary function compared to emotional support, as previously presented, and knowledge exchange, to be presented next.

Drawing on the conceptual framework, we can frame the instrumental support that mothers' networks provide and facilitate as an element of activism, by focusing not on the who, why and how of activism but what it affords (Dokumaci, 2019). In this case, helping to meet the basic needs of families and ensure the survival of mothers and children within the peripheries, especially in a context where informality and resource scarcity demand adaptation and improvisation. Both Dokumaci and Kafer (2013), whose work I draw on here, grapple with the discomfort and danger of linking disability with loss and failure, but ultimately recognise that constraint is also a site of 'generative potential to emerge from constraints' (Dokumaci, 2019, p. 492). In this way, we can recognise that the constraints of peripheral areas located at the intersection of multiple sites of oppression also generate resistance to the shrunken affordances within this environment, which leads to microactivist performances - both by individuals and between individuals via networks. In this case, mothers' networks act as a site for facilitating people as affordances by creating affordances for others (i.e., through meeting emotional and basic needs) and providing space for sharing strategies for affordance creation, which will be discussed as information support.

7.3.3. Knowledge exchange - *'That's what empowerment is. People who already understand, talking to you, so you know where your rights are.'*

I present knowledge exchange as a form of microactivism facilitated by mothers' networks, which are the focus here, although I acknowledge that it also occurs outside of networks. Whilst Dokumaci (2020) presents *people as affordances* to focus on the physical environment, I aim to expand this concept, applying it to the non-physical environment, i.e. access to knowledge, noting that access to knowledge can help facilitate access to the physical environment, as will be demonstrated in the first sub-section, below. From her observations of mothers' networks in Canada, Melanie Panitch (2008) noted that, '*everyday*

practices of mothering gave rise to informal networks for comparing notes and experiences and for developing a shared body of personal empirical knowledge'. She calls this a development of '*a more politicised ideology of motherhood…a resource base from which to initiate resistance*.' This observation resembles Kafer's (2013) and Dokumaci's (2019) work on how constriction generates sites of resistance.

Comparing notes, however, allows mothers to recalibrate their ideas about motherhood and share and develop knowledge and strategies for resistance at the individual level, including orientation and guidance to healthcare, education and social care systems. Across all research sites, this practice was generally referred to as knowledge exchange [*PT: troca de experiência*] and seen as a key objective and function of most networks. Practical knowledge-sharing from mother to mother provided informal orientation and guidance to the labyrinthine health, social care and education systems. This included understanding the rights children are guaranteed by law and the systems and services that are supposed to uphold those rights. Since mothers often arrived at disability worlds with very little prior knowledge of where to start or how to get access to services and support their children need, knowledge exchange between mothers was an essential form of support that reduced time, stress and money spent on navigating complex systems.

Orientation and guidance to the system

As outlined in Chapter Six, mothers related how, on becoming a mother of a child with disabilities, they suddenly needed a vast wealth of new knowledge. Therefore, self-education became vital in creating affordances for themselves and their children. One form of self-education was through knowledge exchange with other mothers, especially where there was a common experience of a diagnosis, service or other specific need whereby one mother could provide orientation or guidance to another. This exchange is referred to in the literature as peer advocacy, and it has been suggested that families of colour are more likely to engage in this form of advocacy (Burke et al., 2024). A repeated theme illustrated in the first empirical chapter was that mothers were unaware of their child's rights before being part of networks, as service providers did not usually provide this information, and it was not otherwise easily accessible. However, mothers' networks provided the space to access this information via knowledge exchange. During the group presentations in Bahia, one mother explained how the network helped address lack of rights knowledge - *'I didn't know anything about autism, about my son's rights, you know? So, I now have the right to know about his right to fight, because of [mothers' network]. I was lost…and I believe all of us were.'* She also mentions his '*right to fight*', signalling how she links knowledge received via the network to advocacy at the individual level.

Even when mothers theoretically knew their children's rights, practical knowledge of how to navigate systems to access those rights was often lacking. The support of other mothers

who had previously navigated systems was therefore seen as a key part of empowerment, with networks facilitating these connections between mothers so that this experiential knowledge and information could be passed on horizontally. A mother leader of a network in Rio de Janeiro described how veteran parents, as Ammari (2015) terms it, educate others with less experience within their network.

> *'[Mother 1] arrives and has a child who is five years old, four, right? Four years. But she sees her little friend there who has this... And then [mother 2] has her son who is autistic. And then the conversation between [mother 2] and [mother 1], one exchanges with the other. She, with the experience of her 10-year-old son, will tell [mother 1] that "the world did not end, [mother 1]". He was born with autism, but mine also has autism. He can speak, he can walk, he can study. I managed to turn things around, I got therapy from there, which is what [mother 1] does. [Mother 1] takes people by the hand, even though her son is 5, she managed to instruct the majority of autistic people here in the project.'*

Therefore, networks function as facilitators of knowledge exchange, allowing mothers to know that they and their children have rights they previously did not know existed and how to access support. In this way, we can see how mothers' networks facilitated knowledge exchange at the peer level to pass on microactivist affordance strategies to support microactivism of other mothers at the individual level.

Self-empowerment

Access to information about rights was at times discussed in relation to the empowerment of mothers to fight for the rights of their children to access health and education services, which was noted as a key aim of networks and closely linked to the emotional and instrumental support that they offered. For example, '*empowerment*' was included as a key function of the Autism network in Bahia during the group presentation. Peer support facilitated horizontal information sharing and was also seen to lead to mothers' empowerment to engage more effectively in their struggle through a better understanding of their child's rights and entitlements. We can therefore consider how mothers' networks facilitate knowledge exchange, which leads to empowerment as a starting point for advocacy. Wright and Taylor (2014, p. 23) suggest that empowerment, self-efficacy and advocacy are correlated and that 'parents may be more likely to engage in advocacy efforts if they have a greater sense of self-efficacy.' I interpret empowerment as the belief that one's actions can effect change and therefore provides motivation to act.

Indeed, this is supported by a study in the US showing that empowerment correlates with higher rates of advocacy for parents of children with disabilities at the individual, peer and systemic level (Burke et al., 2024). It may therefore be true that if mothers are

disempowered through lack of knowledge but empowered through knowledge exchange, emotional support and connecting with other mothers, their sense of self-efficacy and likelihood of engaging in systems-level advocacy, or (macro)activism beyond the individual level, increases. We can also interpret this experiential knowledge exchange as an exchange of microactivist performance (Dokumaci, 2019) strategies that mothers can employ at the individual level.

I draw here on Ammari's concept of *networked empowerment*, which builds on empowerment theories to describe how the internet has allowed parents of children with disabilities to network, share resources and explore new ways of advocacy (2015). Research on networks of mothers of children with CZS in Brazil found that mothers' networks produced collective resistance to overlapping systems of oppression through activism, which navigated access to rights and challenged sites of knowledge production (Valente et al., 2024). Similarly, mother networks in this study facilitated knowledge production between mothers by offering a safe space to exchange ideas, advice, and support and co-create solutions through intermediary and advocacy activities, which I will discuss further in the following section. This networked empowerment allows mothers to resist their environments of shrunken affordances by exchanging microactivist performance strategies (Dokumaci, 2019). Mothers are exposed to the microactivist strategies tried and tested by others to build affordances for their children through the process of knowledge exchange.

Knowledge exchange was critical for empowerment, as mothers learned from each other's experiences and gained confidence in advocating for themselves and their children. This occurred individually, but in some cases, the mothers were also empowered to act collectively, to be discussed in the following section. The understandings of empowerment that came out of the network in Rio de Janeiro reflected the idea that one person did not merely give empowerment to another. Still, it was a two-way interaction reliant not only on peer support but also on action on the part of the mother receiving support. This was illuminated during a conversation between mother leader 4 in Rio de Janeiro and mother 5.4, a member of her network. Mother leader 4 explained how mother 5.4 had taken action by following the guidance given to her to get her son's diagnosis. According to the mother leader, '*that's what empowerment is. People who already understand, talking to you, so you know where your rights are...It's the law, it's your right...[Mother 5.4] is no fool, that's why she got [the diagnosis]. She says it's because of me, but it's not, it's because of her.'* Here she is emphasising that action that mother 5.4 took based on the information she received. Yet mother 5.4 also recognises that her action was because, *'you* [mother leader] *implemented an empowerment'.*

Empowerment is explained in critical scholarship, including in the work of Black feminist thinkers such as Patricia Hill Collins, as a dialogical relationship between group experience and knowledge, meaning that changes in thinking through conversation empowers and

leads to resistance through changes in action (2000). Similarly, Freire's work on the importance of dialogue in developing group consciousness and its influence on the development and approaches taken by Brazilian civil society is evident in the use of conversation circles [PT: *roda de conversa*]. Conversation circles were used by many networks in the study to facilitate knowledge exchange towards the empowerment of members. I observe that these conversations and the resulting empowerment of parents came out of the network's aim to bring mothers together to exchange knowledge and support.

Here, empowerment is fostered dialogically through two-way knowledge exchange between mothers based on experiential knowledge, which promotes self-empowerment through conversation. Self-empowerment was seen by mother leader 4 in Rio de Janeiro as an individual choice to act based on knowledge received from peers during conversation exchanges. '*If you help the person in that conversation and that person accepts that conversation and makes their life that way as if it were support for them, they manage to become empowered. I don't empower you, but you empower yourself.'* In this way, the approach of networks that aim to guide and orient mothers to systems by promoting self-empowerment through knowledge exchange with other mothers reflects the approach of Brazilian civil society influenced by Freire and Black feminist thought. Self-empowerment aimed to lead to resistance through action, by guiding mothers in accessing systems and services they and their children had been excluded from. Although these are actions that would not usually be considered as activism – conversations, guidance, knowledge exchange and changes in action - by combining Dokumaci's theory of microactivist performances (2019) with that of critical scholars like Collins (2000) and Freire (1970) who focus on dialogical empowerment, we recognise these actions as microactivist performances part of mothers' wider struggle for social justice.

Creation and deployment of alternative knowledge

In this section, I look at the alternative, embodied knowledge that mothers, mother-leaders and mothers' networks engaged with to disrupt dominant disability framings within and outside networks. Drawing on Black feminist and critical thought, we can see how sites of dominant knowledge become opportunities for resistance by creating and deploying embodied knowledge. Building on Donna Haraway's (1988) notion of situated knowledges, Patricia Collins reflects on Black women's power and potential to reveal new insights about matrices of domination from their specific social location and experiences of multiple systems of oppression (2000). This embodied knowledge, focusing on the body's role in experiential knowledge acquisition, is a key element of situated knowledge, both of which question dominant ideas of objective truth. In applying situated knowledge to disability knowledge, we can draw on the work of Orsini and Smith (2009), who distinguish between biomedical knowledge, knowledge that contests biomedical knowledge, and embodied

knowledge from Autistic individuals deployed by Autism social movements to help advance movement goals.

Embodied knowledge was used internally to influence other mothers within networks. For example, mother leader 1 in Bahia used her own embodied knowledge as an Autistic woman and promoted embodied knowledge materials from other Autistic individuals to the mothers of Autistic children within her network, so '*that they are empowered and believe that their child is capable.'* However, whilst many mothers accepted this, she also noted, '*many do not accept this information. [They] want to continue calling their child a blue angel*[20]*, want to continue calling their child special, want to continue saying that they are beings of light.'* Her observation highlights the varied approaches to understanding and advocating for children with disabilities within and across communities and how networks could facilitate and provide space for the emergence of alternative perspectives. I also reflect here on the positionality of mother-leaders, who could use networks to deploy embodied knowledge, which also contributed to creating networks in the first place.

Alternative knowledge production and deployment were also used to plug gaps in situated knowledge within broader spaces (outside of networks) dominated by certain voices and perspectives. For example, mother 6.3 in São Paulo noted, *'when I found out about [my son's] diagnosis, I started looking for some references about autism in black people, right? And also, from mothers who talked about autism within my reality, because I identified with…Autistic, black, poor, peripheral. So, when I didn't find any references, I decided to open my own [web]page.'* By engaging in the production and sharing of embodied knowledge that resisted the white-centric, biomedical and non-disabled domination of knowledge about Autism, this mother created affordances to alternative knowledge exchange between those with shared, marginalised identities. As reflected earlier in this section, knowledge creation and exchange are acts of microactivism facilitated by mothers' networks. This exchange can be crucial for empowering others and, as Panitch (2008) points out, creating a starting point for resistance. We can therefore see knowledge exchange as a component to empowering others, which can also be conceptualised as peer-level advocacy, to engage in microactivist affordance creation at both the individual level and collectively, at the systems level. In the final section of this chapter, I further consider the collective actions of mothers' networks at the systems level as a resistance to shrunken affordances that build on the embodied and alternative knowledge exchange within networks.

[20] The term 'blue angel' is used to refer to Autistic people in Brazil. It comes from the colour blue, a symbol of Autism awareness promoted by the controversial organisation 'Autism Speaks' and other parent organisations that is largely rejected by the Autistic self-advocate movement. The term 'blue angel' has also been criticised for contributing to the infantilization of Autistic people. See: Morais Brilhante et al. 2021.

7.3.4. (Macro)activism - *'And we demanded a meeting. We would like to be heard by the government.'*

In their research on mothers of children with disabilities in the UK, Ryan and Runswick-Cole observe that membership of mothers' networks can lead to new mother identities and engagement in activism, even without self-identification as an activist (2009). This questions the binary and resulting definitions that separate individual and collective activism, to be discussed through the framing of microactivist affordances (Dokumaci, 2019). As discussed in Chapter One, parent activism can be framed as systems-level advocacy, in other words, advocating for wider change to existing systems that will impact people beyond their own child (Burke et al, 2024; Wright & Taylor, 2014). I propose that a better-suited framing for the context of this study to be of the broad term of civic activism, referring to how collective, public action in the form of civic engagement aims to address an issue or conflict that impacts the community and individuals alike (Davies, Evans, & Peterson, 2014). By defining these actions as civic activism, the links between the individual and the collective nature of action are visible rather than obscured, which better describes the activities and motivations of mothers' networks, as outlined thus far.

So far, I have applied the concept of microactivist affordances (Dokumaci, 2019) as performances to describe the individual-level actions of mothers and the peer or community level actions whereby microactivist affordances are shared via mothers' networks, through knowledge exchange. Here, I propose that because the actions of networks focusing on systems change (civic activism) are borne out of microactivist networks, we might refer to these as *(macro)activist affordances*. I coined this term, using 'macro' to highlight the public, collective and systems level nature of this type of action in contrast to the individual level, subtle and often invisible nature of microactivist affordance creation (Dokumaci, 2019). The parenthesis around (macro) indicates the connection to microactivist affordances that blur lines between individual and collective activism. It also shows that macro-level (or systems-level) activism can and does occur sporadically and often simultaneously to microactivist affordance creation at the individual and peer level, via microactivist networks, which are the primary functions of mothers' networks as described earlier in this chapter.

Indeed, for most of the networks in this study, to some extent and at specific points, activities went beyond microactivist network functions of support and empowerment of mothers to a more active stance, focusing on enacting systems change, even if they were not explicit about this in their objectives. For network 2 in Bahia and network 6 in São Paulo, the mother-leaders interviewed were more explicit about the objectives for drafting or improving public policies. However, this was not the only objective for both these networks, as it sat alongside the microactivist objectives and happened sporadically depending on political opportunity. It was beyond the scope of the research to investigate further how these objectives were linked.

Still, it was observed that for network 6 in São Paulo, the public policy objective had become more prominent, with the microactivist network and '*acolhimento*' [EN: welcoming or gathering] of families perhaps acting as a secondary objective to provide political support for the first. For the other five networks included in the study, it appeared that providing support via microactivist networks at the peer level was a primary objective. For these networks, (macro)activism, e.g. engagement in public policy making, only arose on an ad-hoc basis linked to a specific issue identified by network members or mother-leaders at the local or national level. I therefore propose that the mothers' networks in this study facilitated (macro)activism via two main modes, to be presented below.

Ad-hoc, targeted campaigns

Some networks have been involved in running targeted advocacy campaigns, usually at the municipal level, in the form of one-off, ad-hoc campaigns or collective actions—for example, two networks in the study organised public campaigns for accessible public transport. Network 1, in Bahia, ran a public campaign including a physical street protest to persuade the municipal bus company to display information about Autism, including symbols for preferential seating, following high rates of discrimination towards Autistic children and their families by bus drivers and other passengers. Mother leader 1 explained, *'with that…symbol of Autism and the poster… informing about autism, about the importance of respecting family members…we achieved this. I consider it a great victory.'* She saw that by using the symbol of Autism to educate the public, it would help to reduce rates of discrimination towards mothers and their children in public spaces. Although it was unclear how far the campaign had successfully reduced actual instances of discrimination, she saw it as successful, as they had persuaded the bus companies to display the Autism symbol and information.

Likewise, network 7 in São Paulo successfully campaigned for free school transport to take their children to the APAE centre where they attended school. During the conversation circle in network 8, one mother explained how, *'we got together, 15 mothers, and we really went on record. So, we did a protest in [municipality]... we went with placards, we took our children to the city hall…we were even questioned by a superintendent'* As a result of this collective action*, 'they quickly resolved it and the bus showed up the next day.'* She elaborated on how this had improved the situation for the families who now received this transport, *'So today, after what happened, it's a lot better.'* Although this was an ad-hoc collective action, it resolved the identified issue and improved the lives of mothers and their children within the community.

The Zika network in Minas Gerais had also been part of national ad-hoc campaigns related to enacting or changing public policies to get disability welfare benefits for families who had

children with CZS. These campaigns were organised via an umbrella organisation with representatives from local Zika associations, '*who [have] all the information that we pass on to the group and spread on social media*'. While not all these public policy campaigns were successful, others were, including the campaign to access the BPC. Mother leader 5 explained, '*it was our struggle that made it happen*.'

Whilst in the United States, a study on parent activism found little evidence that social media advocacy has resulted in local or national change (Ammari & Schoenebeck, 2015), some mothers' networks in Brazil have been somewhat more successful. Studies on Autism and Zika-related parent activism show that communications strategies using social media, private messaging groups such as WhatsApp, helped parents to gain space, support and legitimation for their demands to be included in public policy elaboration (Diniz, 2021; Rios & Andrada, 2015). In the three examples shared above, we see how microactivist networks, with primary and ongoing functions of providing support to families, also facilitate (macro)activism via ad-hoc campaigns. Whilst not all mothers were physically involved in running campaigns, as members of mothers' networks, they also supported in other ways, such as sharing campaign information on social media and collecting and sharing information via mothers' networks. Through the framing of micro and (macro)activism, we can see how mothers' networks, as microactivist networks, can support (macro)activism, without individual mothers who are members identifying as activists or even actively participating in systems-level actions.

Ad-hoc campaigns sometimes evolved into new civic engagement mechanisms, unlike other examples where engagement occurred through existing structures (see following sub-section). For instance, via network 6 in São Paulo, mothers of Autistic children campaigned at the city hall for education reforms. Mother leader 6 described how '*a demand from the mothers to the city hall…to be heard by the government'* led to an open meeting where city councillors met with a large group of mothers. Because the demands were broad and not easily resolved, such as the case of public transport as above, the action led to a new mechanism being formed, whereby *'the administrations accepted all the demands that were raised. The mothers all had the opportunity to speak and there, in that meeting, the mayor appointed a committee of parents.'* This was an unusual case, and the only one where a council has established a parent's commission that we came across. Since its creation a few months before data collection, the network had facilitated the collection of mothers' demands via Google forms and WhatsApp groups and presented them at meetings. Mother leader 6 described how, *'we bring the demands, and they provide the answers in terms of what is possible and what is short, long, medium term'* which they then fed back to network members via bulletins on WhatsApp and social media. This case shows how networks can mediate and facilitate civic participation for those lacking knowledge or access. Notably, the campaign's success may have been due to the support of a local councillor who was a father of a child with a disability himself. Similarly, other networks developed informal

relationships with local politicians, councils or service providers and were able to engage in local-level advocacy that might be more complicated at a national level.

Systemic, dialogical – civic engagement

In other instances, networks were involved in formal initiatives involving civil society where changes to policy and services were discussed through existing formal mechanisms, for example, via the municipal councils of people with disabilities or other consultation platforms with decision-makers. Whilst most networks usually participated in this type of advocacy at the municipal level, occasionally, there was participation at the national or provincial level. For example, during the data collection phase in Bahia, I attended a civil society consultation to provide feedback on the proposal of the second national plan for people with disabilities 'Living without limits', organised by the National Secretary of People with Disabilities under the Ministry of Human Rights and Citizenship. Mother leaders of network 1 attended and participated in the dialogue to list demands of families, including children and mothers, that were currently not being met by the current disability policy and services. This type of (macro)activism was therefore more systemic and dialogical, using top-down methods of civic engagement rather than bottom-up ad-hoc campaigns as described in the previous subsection.

Interviews with mother leaders revealed that some networks participated in national-level research and policy discussion spaces, such as the annual national health and disability conferences, organised by the Ministry of Health and the Ministry of Human Rights and Citizenship, respectively. These conferences are essential spaces for activism, where civil society can participate in debates on research and policy development and implementation and lobby the government for their interests. For example, mother leader 4 in Rio de Janeiro spoke about using the national health conference to stress the need for policy implementation over new policy creation. She explained*, 'My speeches at the conference were that there is no need for policies anymore. Those that already exist must be fulfilled. They are already guaranteed, we just need to comply.'* Although mother leaders usually participated in these spaces, crucially, they represented the demands and complaints of their members. This demonstrates how mothers' networks facilitated the participation of mothers, who would have otherwise not been represented or present in activist spaces alongside other civil society groups directly or indirectly through their mother leaders. Mothers' networks, therefore, play an essential role in facilitating civic engagement in the form of civic activism. Whilst the (macro)activist functions and aims of networks varied across the study, most networks demonstrated some level of civic activism, providing families with a voice and a means to effect change within their communities collectively.

7.4. Chapter summary

In this final chapter of analysis, I have discussed how mothers' networks in peripheral areas facilitate micro and (macro)activism. This chapter represents the perspectives of mother members and mother leaders of mothers' networks in the states of São Paulo, Bahia, Minas Gerais and Rio de Janeiro, through the meanings attached to the functions and objectives of networks. By providing emotional support, instrumental support and knowledge exchange, mothers' networks facilitate the creation of affordances that enable mothers' survival, wellbeing and empowerment to act individually, via microactivist performances in an environment of shrunken affordances. Mothers' networks also facilitate (macro)activism at the systems level, aiming to create more permanent affordances within the wider environments to benefit other families locally or nationally. This happens in ad-hoc targeted campaigns and via existing dialogical civic engagement mechanisms.

I have aimed to bring these debates together through an engagement with the activism literature and application of microactivist network theory, which is an extension of Dokumaci's microactivist affordances and people as affordances (2019, 2020). These individual and collective actions can be seen as a response to and strategies for dealing with the difficulties of access and daily struggles outlined in the first empirical chapter. They constitute diverse, creative solutions to inaccessibility that constitute repeated and ongoing 'performances' that build new habitable worlds for people with disabilities that are not necessarily recognised as disability activism nor undertaken by people identifying as disabled themselves (Dokumaci, 2019). By applying a critical disability theory of microactivist affordances to the experiences and actions of mothers of children with disabilities in Brazil, we can trouble understandings of disability activism by questioning who else can be disadvantaged by and resist the shrinking of affordances and how this can be done individually and collectively through facilitation of mothers' networks.

The support facilitated by mothers' networks emerged as their primary objectives and functions to which members attached significant meaning. As suggested earlier, these functions and those enacting them would not usually be classified as part of disability activism. However, by drawing on the theoretical work of crip queer feminists of colour, such as Piepzna-Samarasinha (2018), it is possible to view this form of community support and informal care that networks provide to families as a form of resistance to structures of oppression because they provide crucial community based survival strategies that do not rely on state structures. Shared experience is related to collective identity and collective struggle for rights, which mothers liken to family. Despite the absence of activist identities, we can therefore view mothers' collective care actions as forms of resistance to oppression, and one form of disability activism.

In this chapter, I further argued that mothers' microactivist networks have developed as essential and, in some cases, influential tools that go beyond providing emotional and practical support to mothers and their children. Whilst mothers' microactivist networks also form part of mothers' care networks, which are essential for wellbeing, they can also facilitate individual and collective action through support, knowledge exchange, mediation, negotiation and civic activism. However, the study also identified substantial barriers to sustaining and forming networks, including activist burnout, financial issues and impacts of the COVID-19 pandemic.

This chapter has sought to demonstrate how the consideration of the experiences of mothers and children with disabilities in peripheral areas calls for greater recognition of the small everyday micro-activist performances that mothers engage in daily. These include non-physical acts such as self-education and advocacy, and the ways in which these embodied knowledges are deployed across microactivist mother networks via knowledge exchange. I aimed to show how some networks further facilitate civic engagement through this knowledge exchange and, more specifically, civic activism, by creating ways in which the concerns and demands of mothers can be represented and addressed in various political spaces.

Chapter 8: Conclusion

8.1. Introduction

In this final chapter, I draw together the analysis presented across the three empirical chapters, Five, Six and Seven, to answer the central research question: how do the experiences and actions of mothers of children with disabilities in peripheral Brazilian communities challenge dominant understandings of disability activism? In doing so, I also revisit the secondary questions that guided this research: how are mothers' experiences shaped by the information and services available to them, and how do their individual and collective actions respond to the state's failure to provide adequate care and support for them and their children?

To answer these questions, I engaged with a Critical Disability Studies (CDS) framework, adopting a political/relational reframing of disability, care, and activism through the intersectional lens of microactivist affordances (Dokumaci, 2019; 2023) and inspired by the work of Alison Kafer (2013). This framework enabled an analysis that situated disability not solely within the body or individual experience but within broader systems of power and oppression, offering a relational and spatial understanding of disability as something produced through unequal structures. I collected and analysed rich qualitative data using visual and creative participatory methods in collaboration with civil society partners, aligning with the disability rights principle of *"nothing about us, without us"* (Charlton, 2000). The research employed an abductive thematic analysis cycle and participatory analysis with the partners, drawing on the CDS framework and existing literature on the actions and experiences of parents of children with disabilities.

This thesis advances the argument that traditional, binary understandings of disability activism, which is often grounded in a disabled/non-disabled dichotomy rooted in Western theory and static disability identities, fail to capture the lived realities of mothers and people with disabilities in peripheral contexts. Where disability is shaped by intersecting forms of oppression, including racism, classism, and sexism, dominant frameworks can be absent, inapplicable, or even exclusionary. In such contexts, disability activism frequently emerges not through formal or recognised channels, but through informal, embodied, and everyday acts of resistance and care by mothers navigating limited choices under precarious conditions. While ableism remains prevalent and not all responses contribute to liberation, broadening narrowly defined conceptions of activism, often assumed to be universal, opens space for cross-issue collaboration and strengthens intersectional approaches.

A central contribution of this thesis lies in its contextualisation of disability activism within Brazil's peripheral areas. It draws on and expands the Brazilian concept of the periphery, as a plural, collective identity and a site of both precarity and resistance, to explore how

intersecting systems of oppression structure the lives and resistances of mothers of children with disabilities. Through this lens, the thesis introduces the concept of *shrunken affordances* to describe how environmental constraints, such as inaccessible services, medical neglect, and a lack of state support, create forms of slow violence (Nixon, 2011) that debilitate both children and their caregivers. Building on Dokumaci's (2019) notion of shrinking affordances, this concept emphasises the enduring, state-structured nature of limited opportunities in peripheral settings, and the creative responses they demand.

Ultimately, the thesis challenges identity-based and individualised conceptions of disability rooted in dominant Western frameworks. It reframes disability as relational and systemic, shaped by the caregiving role and structural constraints faced by mothers in the periphery. By foregrounding *shrunken affordances* as a product of intersectional oppression, this research offers a more expansive, politically grounded understanding of disability activism and reimagines who is included within it.

In response to the final research question of how mothers' individual and collective actions address/resist failures of the state to provide disability information and support in peripheral areas, the concept of *people as affordances* (Dokumaci, 2020) is expanded and applied to how mothers enact creative, everyday forms of resistance and care that generate new disability worlds for their children. Disability activism plays out in the microactivist performances of mothers, in response to the shrunken affordances: undiagnosis, medicalisation of disability, lack of post-diagnostic care and support, lack of provision and affordability of healthcare, denial of social assistance and precarity (see Chapter Five). These actions include microactivist performances enacted at the individual or family level, which involve world-(re)imagining, self-education, and fighting the system (see Chapter Six). Additionally, the thesis broadens the application of people as affordances (ibid) to include sustained, strategic acts (e.g., seeking diagnoses, advocating for rights, navigating bureaucracy) by framing these as *microactivist performances* within the context of *shrunken affordances*.

However, through (macro)activist networks, mothers engaging in microactivist performances at the individual level can connect, providing emotional support, instrumental support, informational support, and crucially, knowledge exchange, that allows them to support each other's microactivist performances as well as facilitate engagement in what I term (macro)activism. I define (macro)activism as actions that focus on systems-level change through ad-hoc campaigns in response to a specific systemic issue or systemic and dialogical civic engagement in existing channels. However, I stress that in this case, (macro)activism is inherently linked to, and would not exist without, the microactivist performances at the individual, family and peer levels. I indicate this through the use of parentheses. Using this framework makes visible that mothers' networks attempt to counteract shrunken affordances and empower mothers to create and share strategies for affordance creation in their environments, both individually and collectively, through micro

and (macro)activist affordances. By framing activism as a continuum influenced by relational dynamics, collective efforts, and the specific contexts in which it occurs, this thesis aims to make visible how mothers of children with disabilities in marginalised settings reinterpret and expand the notion of political action within the disability rights space.

8.2. Theoretical contributions

Contextualising intersectionality through the notion of periphery

The first theoretical contribution of the thesis is that I mobilise and develop the concept of the periphery to apply a contextual understanding of intersectionality. This contribution is significant because it advances debates on the links between disability and other systems of oppression and how resistance to oppression manifests in marginalised settings. As a result of this thesis, we see that the shrunken affordances of the periphery, including poor service provision, medical negligence, lack of physical accessibility, bureaucracy and waiting lists, judicialisation of disability welfare benefits amongst other constrictions of the environment demonstrated in Chapter Five can lead to the debilitation of both children and mothers as a form of slow violence (Nixon, 2011). Mothers experience disability, not necessarily as people with impairments themselves, but on account of their proximity to and complete responsibilisation for their children, in combination with their racial, gender and socioeconomic identities and geographic locations within peripheral areas, where survival is not guaranteed. In some cases, this leads to the debilitation of mothers alongside their children, for example, through worsening of health and well-being and in the most extreme cases, unavoidable deaths because of lack of access to life-saving treatment. Reflecting on the intense marginalisation within peripheral environments, through systems that classify, exclude, pathologise, and disempower both mothers and their children, highlights the importance of embracing a political and relational approach to disability (Kafer, 2013). This perspective moves beyond binary, identity-based frameworks that often dominate both disability studies and activist discourses.

Shrunken affordances as a state and a site of interaction

This directly relates to the concept of *shrunken affordances*, which I adapt from Dokumaci's notion of "shrinking affordances." While Dokumaci (2023) uses 'shrinking affordances' and *shrunken environments* to describe the ongoing process in which environments become less accommodating to individuals, I use *shrunken affordances* to emphasise the *interaction* between state-driven contraction of possibilities in peripheral areas and certain bodies. This subtle but important shift, from the *process* of shrinkage to its *permanent state*, better reflects the reality in Brazilian peripheries, where affordances to healthcare, education, and safety are not simply diminishing but have already been structurally and systematically

restricted through intentional absence of the state (Instituto Update, 2018) and policies that inflict slow violence (Nixon, 2011). Moreover, the concept of *shrunken affordances* retains the focus on the interactive relationship between body and environment, while incorporating the broader historical context and political identity, a plural and collective identity that provides 'a place and a point of view to fight in the world' (Pedreira et al, 2018, p.14) that shape peripheral existence. This framing enables a more comprehensive understanding of how intersectional oppression is embodied, lived and resisted, which single-axis identity-based models of disability and activism do not capture.

Reclaiming the notion of the periphery

In Chapter Six, I expand the concept of the periphery through the application of microactivist affordances by acknowledging that environments of shrunken affordances can be sources of generative potential, offering possibilities for emergence and transformation (Kafer, 2013; Dokumaci, 2019; hooks, 1989). Moreover, microactivist affordances enable the creation of inventive responses to the scarcity of viable opportunities, forming repeated and sustained acts that gradually shape new, liveable worlds for children with disabilities (Dokumaci, 2019) within the periphery. Based on my discussions with project partners, readings of work produced from the periphery and by some mothers themselves, as demonstrated in Chapter Five, there is an indication of an appropriation or reclaiming of the notion by the community that forms part of their resistance. I do not claim that all mothers or indeed all community members engage in this reclaiming or use of the term, and observe that it seems to occur more at the level of periphery leadership and academics.

By expanding the theory to engage with Puar's (2017) concept of debility and including an intersectional analysis that is contextually grounded throughout the empirical chapters, I further develop the concept of the periphery. For example, in Chapter Five, the periphery is presented through the concept of shrunken affordances, whereby systems of disability, gender, race and social class intersect to shrink the affordances available in the environment, to quality healthcare, education and economic opportunities, shaping the experiences of motherhood and childhood.

Intersectional expansion of microactivist affordances

This thesis also contributes to expanding Dokumaci's (2019) concept of microactivist affordances by applying intersectional analysis and by developing the concepts of the periphery and shrunken affordances. The periphery, as understood in the Brazilian context, offers a powerful lens through which to better capture intersecting systems of oppression, as it encapsulates not just geographic marginality but also structural and political exclusion, connecting with Puar's concept of debility. Viewing the periphery as a 'site', both spatial and

experiential, highlights how intersecting systems of oppression, such as race, class, gender, and disability, converge in the lived experiences of those who inhabit these spaces. This framing allows us to move beyond single-axis analyses and instead see how oppression is produced through the interaction of bodies and environments shaped by historical neglect, racialised governance, and state violence.

Whilst Dokumaci's theory of microactivist affordances lends itself to an intersectional application, Dokumaci does not interrogate this to its full potential in her work, as outlined in Chapter Two. This thesis aims to enrich the framework by questioning who engages in microactivist performances to secure access, in which settings, and why, moving beyond a disability lens. It does this by offering an intersectional expansion of Dokumaci's (2019) interpretation of affordances to show how systems of race, gender, and social class intersect with disability to produce shrunken affordances in peripheral contexts.

Expanding people as affordances to mother-child relationships

The thesis advances a novel application of Dokumaci's (2020) theory of people as affordances. Previously, this has only been applied in the general context of family members providing physical support and care to people with disabilities, which Dokumaci (ibid) conceptualises as 'care intimacy' based on the work of Mia Mingus (2011). I expand and apply this concept in two ways. The first is to apply people as affordances to mothers of children with disabilities. I justify this extension by arguing that the experiences of mothers and their children are distinct and yet also inherently *shared* through the responsibilisation of care via familism, simultaneously shaped by experiences in the periphery. Mothers' experiences as affordances are perhaps distinct from those of other care relationships because of the expectations of motherhood shaped by gender. In this way, mothers are both impacted by and act to resist the shrunken affordances that they and their children share in the periphery.

The second novel application of people as affordances is that I expand it to acts (or non-acts) that do not provide immediate access or care in the way that Dokumaci (2020) applies it (e.g. lifting someone, preparing food, not touching someone to avoid creating pain, undertaken in an unspoken and spontaneous manner). Instead, I use the concept of people as affordances to explore the ongoing, drawn-out and repetitive actions mothers of children with disabilities undertake to create access for their children to a medical diagnosis, a school place, or a disability benefit. Here, I conceptualise these actions to develop affordances also as microactivist performances, which include critiquing dominant disability narratives and ideas of 'normality', self-education, and fighting the system through actions such as 'making a scene', 'running after' professionals, or giving up their jobs to ensure their child access to healthcare or education (Chapter Six).

By utilising people as affordances with an intersectional analysis, it reveals how the systems of gender, disability, race, and social class come together in the periphery to influence experiences of motherhood (Chapter Five) and the actions that mothers of children with disabilities must engage in within contexts of shrunken affordances (Chapter Six and Seven) to ensure their child's survival and wellbeing. The findings, therefore, reaffirm the importance of applying an intersectional lens, highlighting that motherhood of children with disabilities in peripheral contexts can be qualitatively different from other motherhood experiences. The use of microactivist affordances may offer a more nuanced understanding of the complex intersectional systems of oppression at play in these settings and thus contribute to a deeper understanding of disability in peripheral contexts.

Development of microactivist networks and (macro)activism

Another theoretical contribution is the extension of the theory of microactivist affordances beyond the individual level, to the peer and systems level, through the development of the concepts of *microactivist networks* and *(macro)activism*, presented in Chapter Seven. By focusing on mothers' support networks, we see how mothers' networks emerge to develop and exchange strategies for creating possibilities within environments of shrunken affordances at the individual/peer level and at the systems level. The concept of microactivist networks reaffirms the notion of the periphery as a site of 'generative potential to emerge from constraints' (Kafer, 2013, p. 492) and contributes to the work of crip queer feminists of colour who suggest that informal community care networks provide space to generate survival strategies that do not rely solely on state structures (Peipzna-Samarasinha, 2018). The application of microactivist affordances showed that disability activism occurs within and is facilitated by mothers' *microactivist networks*, helping mothers navigate the gaps left by state neglect by providing emotional, informational, and practical support, enabling both individual (micro) and collective (macro) activism.

Chapter Seven demonstrates that these networks facilitate this process through knowledge exchange, informational support, instrumental support and emotional support, which empowers mothers to engage in microactivist performances at the individual and family level. Furthermore, this chapter explores how microactivist networks can, in some cases, facilitate engagement in (macro)activism, meaning collective activism focusing on systems change locally or nationally. I develop these concepts; microactivist networks and (macro)activism, in tandem, underscoring the interdependence of these forms of activism and how personal, everyday actions can lead to broader systemic change, especially in peripheral contexts often overlooked in parent activism literature. Microactivist networks primarily facilitate microactivist affordances of mothers at the individual and family level through empowerment, but at times they also lead some mothers to engage in (macro)activism. Yet, I suggest that (macro)activism does not occur without microactivism - the personal and the political are deeply connected here. This is significant because there

has been little exploration in the parent activism literature that explores the relationship between individual-level activism and engagement in systems-level activism of parents (except some works by Burke et al. and Ryan and Runswick-Cole already referenced), especially within peripheral contexts.

The thesis aimed to demonstrate how the actions of these mothers broaden the scope of disability activism to include relational, embodied, and intersectional struggles in peripheral spaces, rooted in care, survival, and community resistance, rather than solely identity or rights-based discourse. This challenges dominant understandings of disability activism, which is often framed in binary, identity-based terms (disabled/non-disabled). By centring the experiences of mothers who are not identified as being disabled themselves but become intimately involved in and impacted by the system of disability through care and responsibilisation, as well as through their experiences concerning other intertwined systems of oppression, we can reflect more broadly on the nature, conceptualisation and future of disability activism from different vantage points.

8.3. Empirical contributions

In addition to the theoretical contributions outlined, this thesis contributes empirically to Critical Disability Studies literature and to activism literature in Brazil. As noted, particularly in Chapter One, perspectives of families with children with disabilities in peripheral communities are rarely represented in mainstream Disability Studies or mainstream disability activism and, as such, have been historically sidelined. This underscored the importance of generating more understanding from this underrepresented viewpoint. By seeking the views of mother-leaders and professionals working in these contexts, I generated new empirical insights into mothers' experiences and activism.

For example, in Chapter Six, the data demonstrates how parent support networks in peripheral areas facilitate instrumental support via mutual aid networks and distributing donations to meet members' basic needs. Furthermore, these networks sometimes facilitated access to services on behalf of members, or even provided services where they were unavailable, inaccessible, or unaffordable, such as physiotherapy through mobilising professional volunteer networks. Existing parent literature has not investigated such mutual aid or facilitation practices, presumably because the focus on middle-class families means that basic needs are more likely to be met via traditional routes, albeit not without struggle. Similarly, the emphasis on empowerment of mothers through knowledge exchange, especially navigating complex and bureaucratic diagnosis processes, is equally unexplored in the existing literature. This is because in other contexts where literature has focused, processes rely more on formal processes and structures, unlike Brazilian systems, whereby

informality is commonplace in circumventing highly bureaucratic processes to access health services (da Silva & Moreira, 2021; Nunes & Lotta, 2019).

8.4. Reimagining research for advocacy

This thesis makes a methodological contribution through its use of a participatory research approach with civil society organisations, advancing this methodology by closely linking it to advocacy at both national and international levels. The participatory nature of the research meant that the data generated throughout the wider project and thesis held practical applicability value beyond academic analysis, directly informing advocacy efforts during the project's timeframe, as illustrated in figure 4.1. The non-academic aims of the project, presented in the introduction, were encapsulated within the research and advocacy report co-produced with research partners, included in Appendix J. Additionally, the research findings were used by partners in multiple advocacy submissions, as listed in Appendix J and elaborated below, as well as more generally to provide evidence to back up their ongoing advocacy efforts.

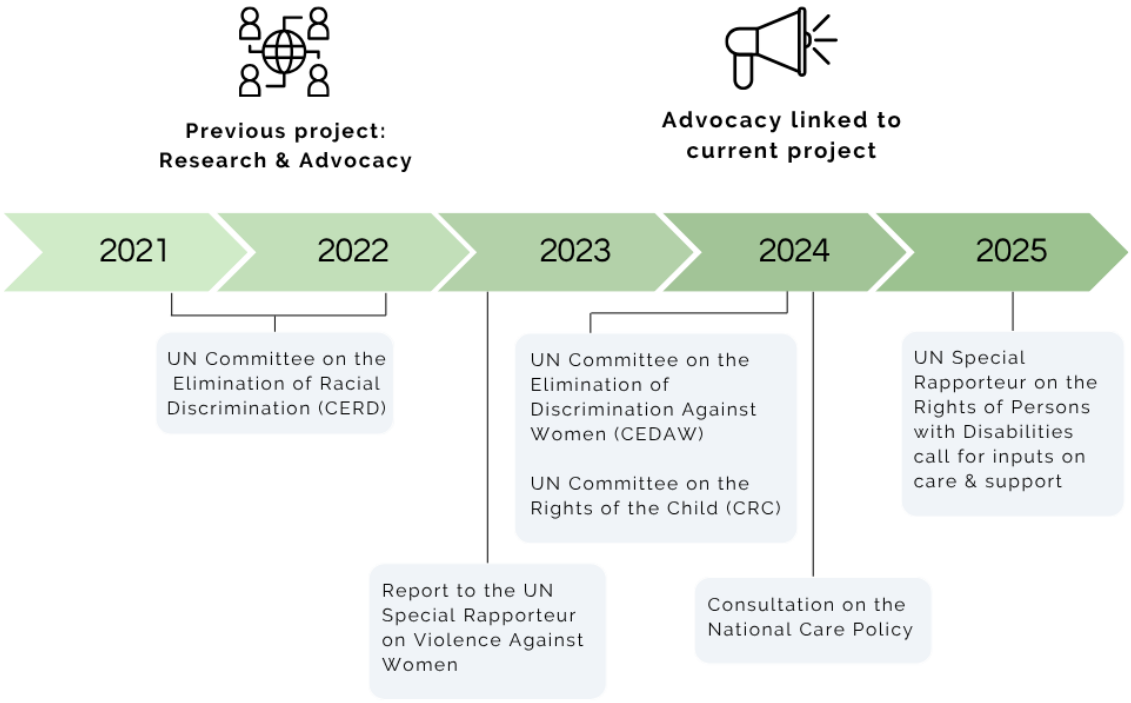


Fig. 8.1. Timeline of advocacy linked to Mothers' Project, using data generated from the research

Within this project, reciprocity was developed and described as '*retorno*' by the participants and partners. To explain the concept, I turn to the work of Millora et al., reflecting on the ethics of doing PhD research in the global south. They posit that 'the notion of reciprocity

within this frame re-orientates 'fieldwork' as more than collecting data but also as an opportunity to research with and stand with communities' (2020, p. 24). Firstly, the participatory design of the research with community members led to co-ownership of the research process and co-production of the outputs for use in advocacy. This allowed project partners to take credit for the research and have ownership of the research project and findings, by using the research findings independently of my involvement and 'outside' of the research project itself, during the 'act' stage of the participatory process, as outlined in Chapter Four.

In collaboration with civil society partners, findings from the project were used in advocacy submissions to several international human rights mechanisms, including the UN Special Rapporteur on Violence Against Women, the Committee on the Rights of the Child (CRC) (Minority Rights Group, 2024a), the Committee on the Elimination of Discrimination Against Women (CEDAW) (Minority Rights Group, 2024b), and the Special Rapporteur on the Rights of Persons with Disabilities in 2025 (see Appendix J for details and links). In one case, a fellow member of VNDI also drew on project data for their doctoral research in Brazil. Beyond formal advocacy, I supported partner organisations by assisting with funding applications and providing references that helped core project partners secure fellowships and paid work.

Partners used some of the data presented in Chapter Five to advance debates on the nexus of racism, ableism, and sexism within the context of civic engagement, particularly during the consultation process for Brazil's proposed National Care Policy, as discussed in Chapter Three. The same data also informed an alternative advocacy report submitted to the CEDAW Committee. Shortly after data collection, partners drew on these findings during a legislative consultation at the Commission on Human Rights at the Brazilian Senate (TV Senado, 2023) and referenced them in public consultations related to the National Care Policy.

In summary, the connection between the research and advocacy work within this project was motivated by the participatory approach with civil society and the co-developed non-academic objectives of the research. These included data collection with the purpose of advocacy towards ensuring the rights and dignity of children with disabilities and their families in peripheral communities, which the data collection and submission to human rights mechanisms and national consultations were able to support. In addition, the objective of addressing the gap between parents and disability activists by engaging both groups in the project was also achieved, both through the process of data collection that involved disability activists from VNDI and mothers' networks, and through the joint advocacy work that included VNDI alongside mothers' networks and other organisations of people with disabilities and civil society organisations to enact an intersectional approach to

disability activism that was cross issue. Whilst reimagining research for international and national level advocacy is not a novel idea, I highlight that it is unusual within a PhD project.

Reflections

I reflect here on some of the tensions and issues related to power and positionality that I introduced in the Introduction and expanded upon in Chapter Four. My understanding of the shifting power dynamics, between myself, institutions, project partners, and participants, and attempts to manage these, was shaped through practice - by working closely with civil society organisations, listening attentively, remaining open to challenge, and being willing to relinquish control over aspects of the research and project process. These dynamics were often characterised by tensions, particularly when academic and non-academic aims did not fully align. Over time, recognising the thesis and the Mothers' Project as distinct yet mutually supportive projects helped to ease some of these frictions.

I also reflect on the burdens that can come with participatory research, especially when working alongside disability activists who often face burnout, public scrutiny, attacks, and health-related challenges. In such contexts, a realistic and ethically grounded approach is essential, which avoids placing undue expectations on partners and participants already navigating multiple structural and personal pressures.

My reflection also centres on the ethical complexities of conducting a Global Development PhD from the global north, particularly in relation to power, positionality, and the tension between institutional imperatives and participatory commitments. I underscore the necessity of ongoing self-reflexivity, an awareness of ongoing colonial legacies, and the importance of reciprocity, manifested through co-ownership, co-production, and sustained support for partner organisations and communities beyond the confines of a project timeline. Rather than seeking to resolve these tensions neatly, I argue for a critical self-awareness and institutional transformation as foundational to meaningful social justice research.

8.5. Limitations of the study

Some limitations of the study stem from my positionality. Whilst there are parts of my identity that inform my understanding of intersectionality and how it can play out in the lives of people with disabilities and their families, I also hold many privileges that protect me from experiencing many forms of discrimination, namely, disableism or racism. My identity, therefore, deeply shapes and limits my perception, understanding and knowledge of the situation of people with disabilities and their families in the context of the research. I have endeavoured to resolve these conflicts in two ways, whilst acknowledging the limitations of these efforts. Firstly, through engaging a participatory research methodology that satisfies the non-academic objectives of the project partners, as outlined in Chapters One and Four.

Secondly, I have attempted to invest in my learning and counteract the limitations of my positionality as far as possible, by engaging with works of anti-racist, Black feminist, intersectional disability, indigenous, critical race and peripheral Brazilian theorists, including non-academic, to inform this work.

The small sample size of professionals was a limitation of the study as it reduced comparability and insights from this perspective. Because of the complex bureaucracy in acquiring authorisation to interview public healthcare service staff, this resulted in a smaller sample of interviewees being recruited who worked exclusively in government-run public healthcare services, and a larger sample size of interviewees who worked in private services or NGO services that the local government partly funds. Overall, the sample size of professional interviewees was small, just five across all research sites, which limits the extent to which this data could be relied on for broader inferences. Interviewing a wider range of professionals working in different sectors would enhance the reflections on service provision and the disability narratives dominant in these spaces, as well as validate reports from mothers, mother-leaders, and project partners.

The study might also have been enriched by drawing on more statistical data from health, education and social assistance systems. This would have helped contextualise the qualitative empirical findings through triangulation and enabled better comparisons of key issues, such as waiting lists, between the data collection sites. Alternatively, a more robust online survey could help to collect data from a wider sample of the population and better demonstrate the scale of issues and comparability across variables. Statistical data is particularly important for policy work, and so this is something that might be particularly beneficial to the civil society partners, especially as data disaggregated by disability, race, gender and other identity characteristics is particularly difficult to obtain, even where it does exist (Viegas & Avery, 2024).

Other limitations of the research design were linked to the design and timing of the workshops. Principally, the time limit of one day per workshop limited the amount of time that project partners could interact with the participants, the time participants had to exchange experiences and interact with each other, and the time available to more closely involve participants in the design of project outcomes and outputs, including continuation of the project. As noted above, a common theme of the feedback from participants during the evaluation was that they would have liked more time for the conversation circle to exchange experiences with other mothers. However, this was impossible due to budget restrictions and large group sizes.

Finally, whilst this thesis explored how mothers and their networks conceptualise and approach their activism, there was insufficient data to draw significant conclusions about how this is understood by mothers who are part of, or not part of, mothers' networks. More

insight from mother leaders would have been beneficial in understanding their activist trajectories, including motivations, political ideologies, identity formation and influences. Longer-term participatory research with mothers and perhaps with fewer networks to understand activism trajectories and conceptualisations, such as identification with and reclaiming of a peripheral identity, may have yielded richer insights and better comparisons between network and mother characteristics. Including a wider range of mothers' networks would have increased the ability to draw comparisons between networks and experiences based on location, diagnosis, and socioeconomic position. Alternatively, or, in addition, digital ethnography could have been expanded to include more mothers' networks, to draw out the differences and similarities.

8.6. Future directions for research

Regarding methodological approaches to this type of research, I suggest investigating how the project's design could be revised to be more participatory, with more (or complete) ownership and leadership of mothers' networks and more input from local organisations of persons with disabilities, to strengthen these collaborations. Whilst there has been a shift to community-led research in some fields, funding structures that favour academic institutions and large NGOs over community organisations, including organisations of people with disabilities, are a barrier to producing more authentic, community-driven research and policy solutions. The exclusion of certain communities from academic research spaces further entrenches this division. Funding barriers aside, drawing on methodologies and frameworks used in other community-based participatory research, such as applying social movement frameworks for systemic change (Trembley et al, 2018), storytelling or re-storying methods (Gravett, 2019); Douglas et al., 2021); PhotoVoice (Kuper et al. 2021; Wickenden & Kembhavi-Tam, 2014), may help to increase ownership of community members and produce richer qualitative data, with wider policy applications.

Further research on how disability activism is understood by and enacted by peripheral communities would help to enrich some of the findings and theorisations around the plurality of disability activism within a Brazilian peripheral context and the forces that are shaping collective peripheral disability identities, specifically. Whilst excellent research and communications work has been done with peripheral community members as journalists, researchers and co-researchers (Pedreira et al, 2018; Instituto Maria e João Aleixo, 2017; Dicionário de Favelas Marielle Franco, 2025; Coalizão de Mídia, 2025), there is still an absence of research produced by people with disabilities in the peripheries, with few exceptions (Minority Rights Group, 2022). Further application of the theory of microactivist affordances to other peripheral populations - including adults with disabilities - would also help to enrich the understanding of relationships between parents' organisations, organisations of people with disabilities and other community networks and structures. This

might provide grounding for better understanding how intersectional disability-led approaches that take explicitly anti-racist and anti-ableist approaches - like the work of the project partner, VNDI - can help to bridge gaps.

Similarly, drawing on the work of crip-made and community care collectives (Lakshmi Piepzna-Samarasinha, 2018; Mia Mingus, 2011), may help to investigate alternative forms of care in the Brazilian periphery context. We know that mothers provide a majority of care and therefore are responsible for creating microactivist affordances for themselves and their children. However, perspectives of other family members and care relationships would help to further test the theory's applicability in such settings.

Including a larger and more diverse sample of professionals across various sectors, including public, private, and NGO-run services, would strengthen the comparative analysis of service provision and the dominant disability narratives within these spaces. For example, whether NGOs such as APAE take a different approach to the government CAPs centres and whether, as a result, mothers' experiences are different. Doctoral research currently being undertaken by another VNDI member, Cátia Brito, that aims to understand how training of health professionals influences disability narratives and approaches will also help to better inform understanding, if it can be applied to the context of mothers' experiences in the peripheries. In addition, comparing families' experiences between services with multi-disciplinary teams with families who deal with separate professionals across separate services would help to expose the structural impacts of service access on mothers' experiences.

8.7. Future directions for policy

The sole focus of this thesis was on mothers' experiences and not on policy *per se*, therefore a detailed policy analysis was beyond its scope. However, the non-academic aims of the project partners, including data collection with the purpose of advocacy and the resulting findings do lend themselves to policy recommendations. As such, a list of policy recommendations was developed with partners and can be found in the project report in the Appendix. I will elaborate briefly on the key recommendations here.

One of the key recommendations stemming from the research findings is for investment and reinvestment in public services, first and foremost, the public healthcare system, SUS, and the social assistance service system, SUAS. As demonstrated in Chapter Five, many of the barriers to accessing these services for families reliant on them are down to chronic underinvestment (da Cunha et al., 2022; Lyra et al., 2022; Massuda, Hone, Leles, De Castro, & Atun, 2018), which has significantly impacted the successful implementation of the National Health Policy for Persons with Disabilities (PNSPCD), as described briefly in Chapter

Three. Policy reform, implementation and budget allocation should be based in consultation with service users and organisations of people with disabilities and their families, complemented by research on service utilisation pathways and trajectories to understand where the barriers to service access lie, particularly to diagnosis and post-diagnostic support, and how they can be removed. More policy-oriented research could also build on the findings presented in Chapter Five, to address some of the barriers in access to services and information that face families in the peripheries.

A second key policy recommendation is to improve access to information in the peripheries, with a specific focus on rights enshrined in the Brazilian Law of Inclusion (LBI), the CRPD and the related policies and benefits. As noted in Chapter Five, being 'deficient in information' forms a key aspect of the shrunken affordances of the peripheries. Progressive policies have no benefit if potential beneficiaries and professionals working in key services are unaware of them. Implementing comprehensive public awareness campaigns in conjunction with community communicators, as well as ensuring proper training of professionals on relevant laws, policies and benefits, would help to ensure that lack of access to information is not a barrier to guaranteeing people's rights.

A third key policy recommendation is to revise the eligibility criteria to the BPC and, separately, approve a National Care Policy that meets the needs of peripheral families with members with disabilities relying on unpaid familial care. It is essential that the BPC is maintained as a separate benefit to offset the extra costs of disability, and benefits intended to remunerate for care do not interfere with BPC eligibility. Additionally, it is essential that the National Care Policy is properly funded, designed and implemented in collaboration with the community to meet the specific needs of people with disabilities and their families in the peripheries. For example, how to ensure that comprehensive and effective policies that ensure remuneration for care are effective for mothers of children with disabilities in peripheral communities, such as the new National Care Policy. A better understanding of the factors influencing fathers' acceptance or rejection of a child's diagnosis linked to family abandonment or involvement may also help to inform policy development in this area and provide better support for families.

Finally, better financing, support and protection of organisations of people with disabilities and other civil society organisations that are doing essential work from intersectional perspectives. Building the capacity of these organisations to do research and develop solutions within their own communities should be a priority. The untapped potential of such organisations to develop sustainable solutions rooted in lived experience could be beneficial in many areas, including providing training to healthcare and social care professionals, family caregivers, community leaders and communicators and collaborating and leading on social justice-oriented research initiative

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Appendices

Appendix A: Mother's Project - team member responsibilities

Data collection and ownership

- Data will be collected simultaneously via the project for different purposes;
- 1. Data collected about the participants collected by the practical civil society project leads, e.g. via registration to workshops. This data is owned by them and may be shared with the academic lead to inform the academic aspect of the research.
- 2. Data collected by the academic lead for the purposes of her PhD thesis via focus groups and interviews. This data will be owned by the University of York and stored according to the UK and university regulations, as outlined in the participant information sheet.
- Once the data is anonymised, practical leads may help with data analysis. They have the right to request access to anonymised data that is stored on the university repository.

Project team and their roles

Lauren Avery - Coordinator and Researcher / academic lead

- Data collection at chosen locations;
- General coordination of projects;
- Interviews with professionals, indicated by the project team;
- Data organization;
- Data analysis coordination;
- Writing of the article/thesis, with analysis of data and contexts.

Days worked: 6 days in Salvador + 6 days in Minas Gerais + 8 days of work planning + 7 days in Rio de Janeiro + 5 days in São Paulo
Totalling: 32 days

Luciana Viegas - Coordination / practical lead (civil society partner)

- Assisting data collection in chosen locations and communities;
- Supporting in organising interviews with professionals;
- Organization and analysis of anonymised collected data
- Coordination of training/workshops directed at the communities that are part of the research; (contact with communities and relatives of people with disabilities)
- Workshop/training planning.
- Writing of the materials offered in the training/workshop.
- Writing a final article/report for publication.

Days worked: 6 days in Salvador + 6 days in Minas Gerais + 8 days of work planning + 7 days in Rio de Janeiro + 5 days in São Paulo // Totalling: 32 days

Maira Cavalcante- Regional Coordination / practical lead (civil society partner)

- Data collection in chosen locations and communities;
- Coordination of training/workshops targeted at 2 communities out of the 4 chosen by the team. (Minas Gerais and Bahia)
- Recruitment/contact with communities and families of people with disabilities.
- Planning of workshops/training (Minas Gerais and Bahia)
- Writing a final article/report for publication.

Days worked: 2 days in Bahia + 3 days in Minas Gerais + 8 days of work planning // Totalling: 16 days

Project team members agree the following:

- To undertake their duties as agreed upon and outlined above.
- Not to disclose the identities of participants who participate in the research without their prior explicit and informed consent.
- At the request of the project members, the names of VNDI and the names of coordinators/practical leads - Luciana Viegas and Maira Cavalcante to be divulged.
- Co-ordinators/practical leads will have the opportunity to review and agree to all information written about them and their organizations in the project before it is published/finalised.
- Informal conversations may provide material for the thesis but permission will be asked to take notes at all times.

Appendix B: Participant Consent Form - Focus Group

Project Title: Access to services and community networks of mothers and children with disabilities.

Thank you for your time in going through the attached participant information sheet. Please read the statements below and mark [X] in the appropriate boxes.

	Yes	No
Taking part in the project		
I have read and understood the information sheet explaining the research project and that I have had the opportunity to ask questions about the project.		
I agree to take part in the project, and I understand what the project is about and what taking part involves.		
I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason for up to three months after my participation in the project.		
I have discussed reasonable adjustments I need so that I can take part in the study e.g. sign language interpreter, easy read information.		
I understand the possible benefits and risks of participating in this research.		
I agree to respect others' privacy and not to repeat any personal information that might be revealed in the focus group to others outside the group.		
I agree to take part in a focus group or interview about how I and my child access support.		
I am happy for members of the partner organisations, [name] and VNDI to be present during the focus group.		
How my information will be used during and after the project		
I understand what information will be recorded from my participation and how this information will be collected.		
I understand how this information will be used in the project, who will have access to this, and what the research will be used for when it's complete.		
I understand my interview or focus group will be carried out, recorded and transcribed by the lead researcher, Lauren Avery.		
I agree that my data may be used by the lead researcher as part of their doctoral thesis, publications and other academic outputs.		

I understand that a pseudonym will be used and anonymisation procedures will be followed appropriately.		
I understand that the organisation I am a member of or work with may be named in the project.		
I give permission for the anonymised information that I provide to be deposited in the University of York's Online Research Data repository so that it can be used for future research and learning.		

Please write your name here (in BLOCK letters): _____

Please sign your name here: _____

Interviewer's name: Lauren Avery, Department of Politics, University of York.

Date: _____

Appendix C: Participant Consent Form - interview

Project Title: Access to services and community networks of mothers and children with disabilities.

Thank you for your time in going through the attached participant information sheet. Please read the statements below and mark [X] in the appropriate boxes.

	Yes	No
Taking part in the project		
I have read and understood the information sheet explaining the research project and that I have had the opportunity to ask questions about the project.		
I agree to take part in the project, and I understand what the project is about and what taking part involves.		
I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason for up to three months after my participation in the project.		
I have discussed reasonable adjustments I need so that I can take part in the study e.g. sign language interpreter, easy read information.		
I understand the possible benefits and risks of participating in this research.		
I agree to take part in an interview about how children with disabilities and their families access support.		
How my information will be used during and after the project		
I understand what information will be recorded from my participation and how this information will be collected.		
I understand how this information will be used in the project, who will have access to this, and what the research will be used for when it's complete.		
I understand my interview will be carried out, recorded and transcribed by the lead researcher, Lauren Avery.		
I agree that my data may be used by the lead researcher as part of their doctoral thesis, publications and other academic outputs.		
I understand that a pseudonym will be used and anonymisation procedures will be followed appropriately.		
I understand that the organisation I am a member of or work with may be named in the project.		

I give permission for the anonymised information that I provide to be deposited in the University of York's Online Research Data repository so that it can be used for future research and learning.		

Please write your name here (in BLOCK letters): _____

Please sign your name here: _____

Interviewer's name: Lauren Avery, Department of Politics, University of York.

Date: _____

Appendix D: Participant Information Sheet

FAQs and Privacy Notice

Project Title: Access to services and community networks of mothers and children with disabilities.

Hello, my name is Lauren Avery. I am a PhD researcher at the university of York in the United Kingdom, and I am working in partnership with Vidas Negras com Deficiência Importam (VNDI) and [mother's network].

You are being invited to take part in this project, which includes research. Before agreeing to take part, please read this information sheet carefully and let us know if anything is unclear or you would like further information.

What is the purpose of the study?

The project aims to understand how support networks empower mothers/caregivers and people with disabilities, facilitating access to information about the rights of people with disabilities, anti-ableism, anti-sexism and anti-racism. The project aims to develop practical interventions that focus on the intersecting forms of discrimination experienced by children with disabilities and women caregivers in marginalized and racialized communities. We would like to understand how the support networks of mothers and people with disabilities can provide alternatives to medicalized narratives of disability and related support, services and treatments that can guarantee dignified and quality lives.

Why have I been invited to take part?

You have been invited to take part because you are involved in the care of children with disabilities and have specific knowledge related to this experience. Your knowledge may come from experience as a family caregiver or it may come from professional experience, as someone who works providing services to children with disabilities and their families.

What will I be asked to do?

You will be asked to take part in interviews with the researcher or a focus group with other participants. You may also be asked to signpost the researcher to other data, organisations or people that are relevant to the study. You may also be invited to join another optional research activity, such as a training, an event or online meetings.

Reasonable adjustments will be made to allow identified participants to take part. This includes if you have caring responsibilities, if you have a disability or health condition, if you have dietary requirements or if you have other needs that can be accommodated, e.g. if you need a sign language interpreter or childcare so that you can take part. Please discuss with Lauren so that adjustments can be planned.

The interview or focus group will be audio recorded, fully transcribed, and kept confidentially as a password-protected and encrypted computer file accessible only to the researcher, Lauren. You are welcome to have a copy of your interview or focus group once the interview has been transcribed.

Will I be paid for taking part?

No. But your costs for travelling to take part in any face-to-face research activities will be covered, as well as food and drinks during the time of the research activities.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given a copy of this information sheet for your records and will be asked to complete a participant information form. If you change your mind, you will be able to withdraw your participation up to 3 months after you participate without having to provide a reason. You do not have to take part but your participation in the study is greatly appreciated.

Has the project got ethical approval?

Yes. The project has been granted ethical approval at Fiocruz (Certificate of Presentation of Ethical Appreciation number: 6964421.6.0000.5091) and from the University of York Economics, Law, Management, Politics and Sociology Ethics Committee (ELMPS).

How will you keep my data secure?

The University will put in place appropriate technical and organisational measures to protect your personal data and/or special category data. For the purposes of this project we will keep any personal data collected about you (e.g. your name and contact details) secure via encryption and password protection on any devices where this information is stored. This data will not be shared with anyone else without your prior written consent and it will be deleted after a period of one year after publication of the research, unless you have indicated that you are happy to be contacted by the research team after this date.

Information will be treated confidentiality and shared on a need-to-know basis only. The University is committed to the principle of data protection by design and default and will collect the minimum amount of data necessary for the project. In addition, we will anonymise or pseudonymise data wherever possible.

Will you transfer my data internationally?

Possibly. The University's cloud storage solution is provided by Google which means that data can be located at any of Google's globally spread data centres. The University has data protection compliant arrangements in place with this provider. For further information see, https://www.york.ac.uk/it-services/google/policy/privacy/.

Will the information the researcher collects be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential, and pseudonyms will be used instead of real names or any details that could identify you. An anonymised transcript of your audio recording will be kept as a secure computer file for up to 10 years after the end of the study, and you will be given a copy. Anonymised data from this study may also be used in conjunction with research data from other studies for academic purposes. All data will be treated in accordance with the UK Data Protection Act 1998. The results of the study will be reported in the PhD thesis, research papers and a research report, which you will receive a copy of.

On what basis will you process my data?

Under the General Data Protection Regulation (GDPR), the University has to identify a legal basis for processing personal data and, where appropriate, an additional condition for processing special category data. In line with our charter which states that we advance learning and knowledge by teaching and research, the University processes personal data for research purposes under Article 6 (1) (e) of the GDPR: Processing is necessary for the performance of a task carried out in the public interest Special category data is processed under Article 9 (2) (j): Processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. Research will only be undertaken where ethical approval has been obtained, where there is a clear public interest and where appropriate safeguards have been put in place to protect data. In line with ethical expectations and in order to comply with common law duty of confidentiality, we will seek your consent to participate where appropriate. This consent will not, however, be our legal basis for processing your data under the GDPR. Data will be processed for the purposes outlined in this notice. Your data will not be shared with third parties, data will be accessible to the project team only. Data will be held within the European Economic Area in full compliance with data protection legislation. You will not be identified in any research outputs.

What rights do I have in relation to my data?

Under the GDPR, you have a general right of access to your data, a right to rectification, erasure, restriction, objection or portability. You also have a right to withdrawal. Please note, not all rights apply where data is processed purely for research purposes. For further information see, https://www.york.ac.uk/records-management/generaldataprotectionregulation/individualsrights/.

Questions or concerns

If you have any questions about this participant information sheet or concerns about how your data is being processed, please contact the researcher, Lauren Avery, in the first instance. If you are still dissatisfied, please contact the University's Acting Data Protection Officer at dataprotection@york.ac.uk.

Right to complain

If you are unhappy with the way in which the University has handled your personal data, you have a right to complain to the Information Commissioner's Office. For information on reporting a concern to the Information Commissioner's Office, see www.ico.org.uk/concerns.

If you would like to complain about another aspect of the project, you can contact one of the project supervisors:

Dr. João Nunes, Department of Politics, University of York, UK – joao.nunes@york.ac.uk
Professor Bryony Beresford, Social Policy Research Unit, University of York, UK – bryony.beresford@york.ac.uk
Dr Denise Pimenta, Fundação Oswaldo Cruz, Minas Gerais, Brazil – pimentadn@gmail.com

For ethical concerns you may contact the Chair of the ELMPS Ethics Committee: Professor Tony Royle, email: elmps-ethics-group@york.ac.uk

What do I do now?
If you would like to hear more about the study or would like to take part, approach Lauren using the contact details above. She will send you a participant consent form to sign and you will be asked again for verbal consent before you take part in the research.

Thank you for your time.

Appendix E - Fiocruz Ethics Committee Approval

INSTITUTO RENÉ RACHOU
FIOCRUZ- MINAS

Plataforma Brasil

COMPROVANTE DE ENVIO DO PROJETO

DADOS DO PROJETO DE PESQUISA

Título da Pesquisa: Usando intersecionalidade para analisar movimentos sociais pós-Zika no nordeste Brasileiro: enfrentando opressões de deficiência nas suas interligações com raça, classe social e gênero.

Pesquisador: Denise Nacif Pimenta

Versão: 1

CAAE: 46964421.6.0000.5091

Instituição Proponente: Instituição Instituto René Rachou/FIOCRUZ Minas

DADOS DO COMPROVANTE

Número do Comprovante: 051683/2021

Patrocionador Principal: Instituição Instituto René Rachou/FIOCRUZ Minas

Informamos que o projeto Usando intersecionalidade para analisar movimentos sociais pós-Zika no nordeste Brasileiro: enfrentando opressões de deficiência nas suas interligações com raça, classe social e gênero. que tem como pesquisador responsável Denise Nacif Pimenta, foi recebido para análise ética no CEP Instituto René Rachou FIOCRUZ- Minas em 18/05/2021 às 16:48.

Endereço: Avenida Augusto de Lima, 1715
Bairro: Barro Preto **CEP:** 30.190-002
UF: MG **Município:** BELO HORIZONTE
Telefone: (31)3349-7825 **Fax:** (31)3349-7825 **E-mail:** cepsh-cpqrr@cpqrr.fiocruz.br

Appendix F - Codebook

1. Theme: Access – acesso

1A – Sources of information – fontes de informação

Code Name / Nome de código	Fontes de informação	Sources of information
Definition / definição	Fontes de informação sobre direitos, benefícios e serviços	Sources of information about rights, benefits and services
When to use / Quando usar	A ser usado no contexto de informação fornecendo pelo governo ou profissionais de serviços	To be used in the context of info being provided by government or service professionals.
When not to use / Quando não usar	Não a ser usado para informação através de redes de suporte.	Not to use for information via community support networks
Example 1 / Exemplo 1	*Em relação aos direitos, a assistente social ela faz esse papel de estar falando sobre os direitos deles, né, o que eles tem em relação a..A oportunidade mesmo de até de emprego*	*In relation to rights, the social worker plays this role of talking about their rights, right, what they have in relation to... The opportunity of even employment.*
Example 2 / Exemplo 2	*E as guias para as terapias, né? Terapia com fono, com psicólogo, com terapeuta ocupacional, tantas horas, et al. Então, me aqui e procure a clínica onde o seu filho vai fazer a terapia*	*And the guides for the therapies, right? Therapy with speech therapist, with psychologist, with occupational therapist, so many hours, etc. So, come here and look for the clinic where your son will receive therapy.*

1B – Lack of access to information – a falta de acesso à informação

Code Name / Nome de código	Falta de acesso à informação	Lack of access to information
Definition / definição	A falta de informação sobre direitos, benefícios e serviços.	A lack of information about rights, benefits or services.
When to use / Quando usar	Quando está relatado de que informação não está sabendo ou recebido.	When it's reported that information is not known or received.
When not to use / Quando não usar	Para informação medical sobre um diagnóstico ou condição.	For medical information about a diagnosis or condition.
Example 1 / Exemplo 1	*eu falo que são duas cidades tão próximas e a realidade completamente diferente. Completamente diferente. A isso você vê que são pessoas que as vezes não conseguem fazer um link ali no celular, ela não tem um entendimento, então aí por isso que a informação demora a chegar, mais para eles.*	*I say that they are two cities so close and the reality is completely different. Completely different. You can see that these are people who sometimes can't open a link on their cell phone, they don't have an understanding, so that's why the information takes a while to arrive, especially for them.*
Example 2 / Exemplo 2	*Nao, ela nao fez um encaminhamento, so fala "o, você vai lá na clinica da família, clinica da familia vai te mandar por CRAS. Lá você vai ter todas as informações." Só que me falaram só isso.*	*No, she didn't make a referral, she just says "oh, you go to the family clinic, the family clinic will send you through CRAS. There you will have all the information." That's all they told me*

2C- Access to Healthcare. -acesso à saúde

Code Name / Nome de código	Acceso à saúde	Access to healthcare
Definition / definição	Acesso à qualquer serviços de saúde, seja de SUS ou privado.	Access to any healthcare services, whether public or private.
When to use / Quando usar	Quando um participante está especificamente falando sobre acesso aos serviços da saúde.	When participant is specifically talking about healthcare service access.
When not to use / Quando não usar	Não a ser usado para serviços sociais ou educação.	Not to be used for social services or education.
Example 1 / Exemplo 1	*Pra gente que mora na comunidade é muito mal assistida. Eu moro em [bairro] e assim, agente da saúde esse tempo todo, desses dois anos desde acidente da [filha] foi na minha casa duas vezes.*	*For people who live in the community, it is very poorly supported. I live in [neighborhood] and so, the health worker this entire time, in the two years since [daughter's] accident, has been to my house twice.*
Example 2 / Exemplo 2	*E o privado a gente não tem como custear, né? Aí, não tem como custear, como é que vai ser, entendeu? Eu vou chegar num atendimento privado e não tenho dinheiro pra pagar. E tem gente que não tem o LOAS, né? Não recebe o LOAS. O benefício assistencial pra pessoa com deficiência. Aí você imagina, essa pessoa que realmente precisa para custear um atendimento, não tem, entendeu? Então fica difícil, a*	*And we can't afford the private sector, right? So, there's no way to pay for it, how would it come to be, understand? I go to a private service and I don't have the money to pay. And there are people who don't have LOAS [benefits], right? Do not receive LOAS. The assistance benefit for people with disabilities. Then you imagine, this person who really needs it to pay for a service, doesn't have it, understand? So, it gets difficult, we are left at*

	gente fica gente à mercê... A gente fica a mercer do SUS, entendeu?	*the mercy... We are at the mercy of the SUS [national health system], understand?*

2D – Access to education

Code Name / Nome de código	Acesso a educação	Access to education
Definition / definição	Acesso a pre-escola, escola, colégio, faculdade ou outro tipo de educação formal.	Access to pre-school, school, college, university or other types of formal education.
When to use / Quando usar	Quando participante mencionar acesso a educação em geral.	When a participant mentions access to education in general, including barriers, e.g. transport.
When not to use / Quando não usar		When education is mentioned in passing and is not the focus.
Example 1 / Exemplo 1	*Essa escola ali tem 30 alunos com deficiência, ou seja, é uma escola inclusiva. Aí você vai lá, na prática não tem [inclusão], você tem que entrar, ir para Secretaria de*	*'That school has 30 students with disabilities, that is, it is an inclusive school. So you go there, in practice there is no [inclusion], you have to go in, go to the Education Department*

	Educação fazer barraco. Eu até fui, eu fiquei famosa sem saber, né?	*and make a fuss. I even went, I became famous without knowing it, right?*
Example 2 / Exemplo 2	*Minha briga hoje, até hoje é essa. Tá lá, tá. Mas eu não consigo, Não tem jeito. Eu consegui um acompanhamento para minha filha na escola e eu pago a escola, mas não tem.*	*My fight today, to this day, is this. It's there, it's there. But I can't do it, there's no way. I managed to get accompaniment for my daughter at school and I pay for the school, but there is none.*

3. Theme: Support network - rede de apoio

3A - Support network as a collective

Code Name / Nome de código	Rede de apoio como coletivo (entre mães)	Support network as a collective (between mothers)
Definition / definição	Sinalizando a resistência coletiva / da comunidade através do apoio coletivo	Signalling collective / community resistance via collective support
When to use / Quando usar	No contexto das redes de apoio comunitário	In the context of community support networks
When not to use / Quando não usar	Não no contexto de 'luta' individual ou apoio familiar	Not in context of individual 'fight' or family support
Example 1 / Exemplo 1	*Então como sempre [mãe] me chama, eu tô junto com ela, tem uma luta, tamo aí né. Porque eu tô aí pra ajudar. Porque a gente tem que se unir pra ajudar ela, porque a gente tem que lutar pelo benefício dos nossos filhos, pelos direitos dos nossos*	*So, as always [mother] calls me, I'm with her, there's a fight, we're there, right? Because I'm there to help. Because we have to come together to help her, because we have to fight for the benefit of our children, for the rights of our children. If we are discriminated against.*

	filhos. Se a gente é discriminada.	
Example 2 / Exemplo 2	*Você só tá aqui por causa da Cesta Básica? Não, você tá aqui porque somos um coletivo e precisamos nos fortalecer.*	*Are you only here because of the Support Basket? No, you are here because we are a collective and we need to strengthen ourselves.*

3B – Support network as mutual aid (practical support)

Code Name / Nome de código	Apoio mútua	Mutual aid
Definition / definição	Partilha de recursos ou apoio prático, interdependência e não dependência nos recursos de estado	Sharing of resources or practical support, interdependence, and non-reliance on state resources
When to use / Quando usar	por exemplo. arrecadação de fundos, doações, cuidados	e.g. fundraising, donations, care
When not to use / Quando não usar	Troca de informações (use troca de informações)	Information exchange (use information exchange)
Example / Exemplo 1	*E tem um centro de fisioterapia que nós construímos, mas o objetivo desse centro nosso é para atendimento da comunidade. Por quê? Na [nome de bairro], no entorno desses bairros aqui, não se tem nada a nível de SUS. De fisioterapia, não existe.*	*And there is a physiotherapy center that we built, but the purpose of this center is to serve the community. Why? In [neighborhood], around these neighborhoods here, there is nothing in terms of SUS [national healthcare system]. There is no such thing as physiotherapy.*

Example 2 / Exemplo 2	*Uma mãe está precisando de um gás. Aí coloca num grupo, aí se junta cada um da o que puder para ajudar, isso aí. é assim que vai. Você tem roupa que não dá em você, você não pode seu filho, então, bem cuidadas que você pode doar para uma criança, a gente coloca no grupo.*	*A mother is in need of gas. So, she puts it in a group, then everyone comes together and gives what they can to help, that's it. That's how it goes. You have clothes that don't fit you, you can't fit your child, so, well-cared for clothes that you can donate to a child, we put them in the group.*

3C – Support network as experiential knowledge & information exchange

Code Name / Nome de código	Troca de experiência e informações	Experiential knowledge & information exchange
Definition / definição	Troca de informações baseada na experiência de navegação de sistema da saúde, educação ou assistência social	Sharing knowledge based on experience of navigating the health, education, or social welfare system
When to use / Quando usar	Encaminhamento para troca de conhecimento entre cuidadores	Referral to knowledge exchange between mothers
When not to use / Quando não usar	Não são informações recibidas de profissionais	Not information from professionals
Example 1 / Exemplo 1	*E aí [mãe 2] tem o filho dela que é autista. E aí a conversa da [mãe 2] com a [mãe 1], uma troca com a outra. Ela com a experiência do filho dela com 10 anos com vai falar pra [mãe 1] que "o mundo não acabou, [mãe 1]".*	*And then [mother 2] has her son who is autistic. And then the conversation between [mother 2] and [mother 1], one exchanges with the other. She, with the experience of her 10-year-old son, will tell [mother 1] that "the world did not end, [mother 1]".*

Example 2 / Exemplo 2	*Conhecer para entender; Uma rede de apoio em geral; esclarecimentos; estimular a participação dos pais e familiares a movimentações em busca dos nossos objetivos no tratamento de nossos filhos e benefícios, né? Que muitas vezes, é... querendo ou não, é... a justiça... a justiça, ele tira da gente o que é direito dos nossos filhos e muitas vezes a gente consegue esclarecimento de uma mãe como deu entrada no BPC, né? Como está tirando o cartão de um passe, um intermunicipal e municipal e que se encontra nesse grupo, que é uma rede de apoio e de esclarecimento*	*Know to understand; A support network in general; clarifications; encourage the participation of parents and family members in movements in pursuit of our objectives in treating our children and benefits, right? That often, it's... whether we like it or not, it's... justice... justice, it takes away from us what our children are entitled to and we often get clarification from a mother about how she entered the BPC, right? How are you getting a card for an intercity and municipal pass and are you in this group, which is a support and information network?*

3D – Psychological/emotional support of mothers

Code Name / Nome de código	Apoio psicológico das mães	Psychological support of mothers
Definition / definição	Apoio de pares entre mães como apoio psicológico	Peer support between mothers as psychological support
When to use / Quando usar	Por falar sobre como as redes de apoio fornecem apoio informal à saúde mental	For talking about how support networks provide informal mental health support
When not to use / Quando não usar	Para consultar suporte profissional	To refer to professional support

Example 1 / Exemplo 1	*Porque a gente sabe que quando oferece essa informação, né, que ela não teve acesso ali na clínica, que ela não teve acesso muitas vezes no CAPS, né? Nos lugares de atendimento que é para acolher essas mães, mas na maioria das vezes não acolhe, né? A gente tá salvando vidas, né? Não só da mãe, mas também daquela criança que vai crescer empoderada de quem ele é.*	*Because we know that when we offer this information, right, that she didn't have access to there at the clinic, that she didn't have access to CAPS [Psychosocial Care Centers] many times, right? In places of care that are supposed to welcome these mothers, but most of the time they don't, right? We are saving lives, right? Not only of the mother, but also of that child who will grow up empowered by who he is.*
Example 2 / Exemplo 2	*é como eu disse pra vocês, essa rede aqui é uma fortaleza muito grande. Porque quando a gente tá caindo, que a gente ouve a fala de uma das mãe, a gente se fortalece e diz "eu não tenho nada, eu não tenho nada". E aí a gente busca estar melhor ainda. E é o que essa associação está a fazer comigo e com as outras mães que estão lá. Tá dando essa rede de apoio psicológico e além disso de passar pelos profissionais. Mais essas conversa que a gente tem umas com as outras aqui nos fortalece e nos levanta e nos sustenta.*	*It's like I told you, this network here is a very big fortress. Because when we are falling, when we hear what one of our mothers say, we get stronger and say "I have nothing, I have nothing". And then we try to be even better. And that's what this association is doing to me and the other mothers there. It is providing this psychological support network and, in addition, passing through professionals. But these conversations that we have with each other here strengthen us, lift us up and sustain us.*

3E – As intermediary / advocacy with the state

Code Name / Nome de código	Como intermediário/ advocacia junto ao estado	As intermediary / advocacy with the state
Definition / definição	Quando a rede faz a mediação com serviços estatais para negociar o acesso individual ou fazer uma mudança estrutural para o acesso coletivo	When the network mediates with state run services to negotiate individual access or make a structural change for collective access
When to use / Quando usar	Para encaminhamentos, campanhas e negociações (geralmente redes mais formalizadas)	For referrals, campaigns, protests and negotations (usually more formalised networks)
When not to use / Quando não usar	Para atos individuais de mediação de uma mãe para seu próprio filho	For individual acts of mediation by a mother for their own child
Example 1 / Exemplo 1	*O nosso [papel] é muito intermediador. Entre família e clínica, então a gente consegue parceria com clínicas, exames, aí a gente faz entre famílias e empresa privada, desconto, farmácia, aortas (?), essas coisas, entendeu? Enquanto rede de apoio.*	*Our [role] is very intermediary. Between family and clinic, so we get partnerships with clinics, exams, then we do it between families and a private company, discount, pharmacy, orthosis, these things, understand? As a support network.*

Example 2 / Exemplo 2	*Nós reunimos. Teve uma época que nós nos reunimos, 15 mães, e fomos mesmo pra record. Então fizemos um panelaço em [municipal] mesmo. Rapidamente resolveram e o ônibus apareceu no outro dia. Você entendeu? Porque nós fomos com placa, levamos os filhos na porta da prefeitura, então fomos até questionado por um superintendente. Não precisava desta situação. Aí eu respondi "como não precisava dessa situação, se nós viemos aqui e vocês mandavam nós levar nossos filhos de trem?" Porque é o transporte lá eles entram com transporte e aqui a educação. Então hoje, depois do acontecido, melhorou muito.*	*We gathered. There was a time when we got together, 15 mothers, and we really went on record. So, we did a protest in [municipality]. They quickly resolved it and the bus showed up the next day. Understand? Because we went with placards, we took our children to the city hall, so we were even questioned by a superintendent. It didn't need this situation. So, I replied, "how did it not need this situation, if we came here and you told us to take our children by train?" Because it's transport there - they provide transport and here, education. So today, after what happened, it's a lot better.*

3F – Acolhimento

Code Name / Nome de código	**Acolhimento**	**Acolhimento**
Definition / definição	Acolhimento, guia e suporte ou seja um atitude de inclusão, um abordagem humanizado.	welcoming, guidance and support or an attitude of inclusion, a humanized approach.
When to use / Quando usar	Quando a palavara 'acolhimento' está usado ou um descrição que cabe a definição.	When the word 'acolhimento' is used or description that fits the definition.

When not to use / Quando não usar		
Example 1 / Exemplo 1	*Olha, digo pra você que o [nome de ONG] é uma porta onde acolhe pessoas, seja para morada, como para a escuta, como para os encaminhamentos, como para a vivência.*	*Look, I tell you that [name of NGO] is a door where it welcomes people, whether for housing, for listening, for referrals, or for experience.*
Example 2 / Exemplo 2	*E elas sempre falam e gostam muito do serviço do [NGO] porque a gente faz questão de fazer um trabalho humanizado e personalizado, né, com a família. Então, com a família, então, nosso atendimento é bem diferenciado dos outros, assim, né, dos atendimentos públicos.*	*And they [mothers] always talk about and say they really like the [NGO] service because **we insist on doing humanized and personalized work, right, with the family.** So, with the family, our service is very different from others, like, you know, public services*

4. Background / Intersections

4A. Periphery – 46 codes,

Code Name / Nome de código	**Periférica**	**Periphery**
Definition / definição	Locais de precariedade e violência criados pelo Estado e ausência de provisão estatal, mas também locais de resistência através da produção de conhecimento e do desenvolvimento	Sites of precarity and violence created by the state and absence of state provision yet also sites of resistance through knowledge production and collective development of creative alternative solutions.

	colectivo de soluções alternativas criativas.	
When to use / Quando usar	Quando a palavra ‘periferia’, ‘favela’, ‘comunidade’ etc está usado ou descrevendo.	When the word ‘periphery’, ‘favela’, ‘community’ etc is used or described.
When not to use / Quando não usar	Quando o contexto de periferia não está especificamente mencionada ou relevante.	When the peripheral context is not specifically referred to or relevant.
Example 1 / Exemplo 1	*Você colocar no seu relatório lá que, é tipo assim, a política faz com que as mães periféricas não tenham conhecimento que outras mães que não são periféricas tem, entendeu? E elas chegam lá como se nada tivesse acontecido de obter esses benefícios como nós.*	*You put in your report that it's like this, the policy means that peripheral mothers do not have the knowledge that other mothers who are not peripheral have, understand? And they arrive there as if nothing had happened to get these benefits like we have.*

Example 2 / Exemplo 2	*Não na vida de pessoas negras, negras, mas negras com deficiência e também de pessoas pobres. Porque não é só sobre raça, é também sobre raça. Mas, por exemplo, uma pessoa branca que mora na periferia não tem acesso, porque quem mora na periferia maior parte negra, A gente foi colocado lá, mas quem tá lá por causa da questão de classe, que não tem dinheiro, também tem o mesmo tipo a falta de acesso que uma pessoa negra não tem.*	*Not in the lives of black people but black people with disabilities and also poor people. Because it's not just about race, it's also about race. But, for example, a white person who lives on the outskirts doesn't have access, because those who live in the outskirts are mostly black. We were placed there, but those who are there because of class issues, who don't have money, also have the same type of lack of access that a black person does not have*

4B. Mãe Atípica – 28 codes

Code Name / Nome de código	**Mãe / Família Atípica**	**Atypical Mothers / Families**
Definition / definição	Mãe/familiar (de uma) / criança ou pessoa com deficiência	Mother/family member (of a)/ child or person with a disability
When to use / Quando usar	Quando a palavra ‘atípica’ está usado	When the word ‘atypical’ is used to describe a person
When not to use / Quando não usar	Quandoa palavra não está usado especificamente para desecrever uma pessoa.	When the word is not specifically used to refer to a person.
Example 1 / Exemplo 1	*E a vida de - todo mundo já é corrido, mas uma mãe atípica é muito mais*	*And everyone's life is already busy, but an atypical mother is much more.*

Example 2 / Exemplo 2	*eu não vejo muita diferença, porque os grupos que têm de mães atípicas, com outras patologias, também com outras deficiências*	*I don't see much of a difference, because the groups that have atypical mothers, with other pathologies, also with other disabilities*

4C. Ableism – Capacitismo

Code Name / Nome de código	**Capacitismo**	**Ableism**
Definition / definição	Discriminação baseado em deficiência ou capacidade.	Discrimination based on disability or ability.
When to use / Quando usar	Quando uma situação em que a capacitismo aconteceu está descrevendo.	When a situation where ableism has occurred is described.
When not to use / Quando não usar	Quando tiver discriminação contra deficiência ou estigma.	When disability discrimination or stigma is present.
Example 1 / Exemplo 1	*Eu já sofri por ser mulher negra, de zona periférica, filha de mãe solteira. Imagina todo esse recorte, uma criança autista que ele é lindo, mas a família dele, a minha irmã, cunhado que não deixa nem usar o crachá porque têm vergonha. Como essa criança vai crescer?*	*I have already suffered for being a black woman, from a peripheral area, the daughter of a single mother. Imagine this whole situation, an autistic child who is beautiful, but his family, my sister, brother-in-law who won't even let him wear his [Autistic] badge because they are ashamed. How will this child grow up?*

Example 2 / Exemplo 2	*'Eu tive uma filha prematura, minha filha veio a falecer, nasceu prematura de seis meses, faleceu e a única coisa que a médica falava era assim 'olha, se ela sobreviver ela vai precisar de muita coisa, ela não vai ser normal'.*	*I had a premature daughter, my daughter died, she was born six months premature, she passed away and the only thing the doctor said was, 'look, if she survives she will need a lot of things, she will not be normal'.*

Appendix G - Interview schedule

Interview Schedule – fieldwork, June – August 2023

Research site	Organisation type	Professional title / job type	Date of interview	In-person or online
Bahia	Public – SUS Basic Health Unit	Psychologist	26/7/23	Online
Bahia	Private Psychologist	Psychologist	11/8/23	Online
Bahia	NGO – private-public partnership. Inclusive resident for people with disabilities.	Service manager	15/7/23	In-person
Bahia	Mothers' Network 3 – Abraço Microcefalia	Mother leader	23/7/23	Online
Bahia	Mothers' Network 1	Mother leader	7/7/23	In person
São Paulo	APAE centre	Social worker	4/8/23	In person
São Paulo	Municipal secretary of the department of persons with disabilities	Manager	31/7/23	In person
São Paulo	Mothers' Network 6	Mother leader	28/8/23	Online
Rio de Janeiro	Mothers' Network 8 – Projeto Marias	Mother leaders	22/8/23	In person
Minas Gerais	Mothers' Network 7 – Anjos de Minas	Mother leader	11/12/23	Online

Appendix H - Interview Questions Guide

Research Question	***Target Groups for Interview***	***Interview Questions for Target Group/Activity***
How do mothers experiences and actions / networks challenge understandings of disability activism? How do mothers' individual and collective actions resist failures of the state to adequately provide care and support for children with disabilities and their families in peripheral areas?	*Mothers*	***Activity 1:*** *- What is [network] to you?* *- What are the network's objectives?* ***Activity 2: Mapping information and support – mothers' networks*** ***Aim:*** *to understand what kind of support a caregiver/child receives and from where – e.g. domestic (family), community (church, friends, neighbors, associations), public (school, healthcare), private (paid daycare, private therapy).* ***Activity 3: Access*** *(observation of conversation circle)*

How are the experiences of mothers of children with disabilities shaped by information and service provision in peripheral areas?	*Mother leaders; professionals*	***Interview Questions (Organizers/Professionals):*** 1. What is the profile of the children/families served by your service/network? 2. What are the ways families can access your service/network (can you explain step by step?) 3. If [they] are denied access [to the diagnosis/service], what is the process? 4. What are the waiting lines like for access to your center/service? How many children, teenagers and adults are waiting in line? 5. When do they receive a diagnosis/start care at your health facility? What information do they receive? (about the services available, about the diagnosis, about other support available in the neighborhood? Is there a booklet/handbook/website/form you can show me?) 6. In addition to accessing this service, do families/children usually attend other services or support networks (Example: networks of mothers?) 7. What difference does [support/information network] make in access to knowledge and the type of information they receive? 8. How would you classify the type of information they access from SUS/SUAS/NGOs/network? 9. Do you notice a difference when a mother/caregiver is part of a community support network? 10. Does [the service] indicate or have a referral process to any other community support network or other services? If so, which ones? 11. Does [the service] have a referral process for support services for mothers? (Example: therapies, Specialized Women's Assistance Units (DEAMs), NGOs?) 12. - What is the path families take to access services? If they face any denial of access, what is the process? **About training**

		12. What is your background? During your training, did you receive any teachings about the rights of people with disabilities, about models of disability? Teaching by people with disabilities? *Extra question for professionals who work with Autistic people:* 12. What is your opinion on the idea of 'graduating' from the autism spectrum? 13. Are there other professionals you would like to recommend for the research interview? 14. What do you think about the assessment of the diagnosis of autistic adults and other neurodiversities in the SUS?

How do mothers' individual and collective actions resist failures of the state to adequately provide care and support for children with disabilities and their families in peripheral areas?	*Mother leaders*	***Interview Questions (mother-leaders):*** - How did your network(s) come about ? - How is your network managed and governed? - Do you have official legal status (e.g. CNPJ)? - Who are the network leaders? - Can you talk a little about the work and objectives (or strategy) of your network? - How are the network's work and objectives decided? - How are the network's work and objectives carried out? - How are strategies developed (e.g. advocacy or activism)? Are they influenced by other movements or organizations? - What are your activities/projects? - Where do you receive funding/financial/other support? - Would you classify any of your work or activities as activism (advocacy)? - Is the network ever involved in supporting/starting any campaigns? - How effective has your network's work been in achieving its objectives, i.e. what changes have occurred as a result of your campaign, for example? - What were the main milestones for your network in achieving its goals? - How do your identities and the identities of your mothers (race, gender, social class) influence your activities and approaches to activism? - What are the first questions from your members? - Do you feel that the issues/problems/identities of your members are represented by other organizations? Be it another mothers' organization, NGO or organization of

		people with disabilities? And in the struggle of people with disabilities? Do you notice a gap? - What is the relationship between [network] and other organizations/networks? - Where do you get information to share with your members? What kind of information is it? What about? How is information shared between members? - What do you think is the best way to share the research process and results with mothers in your network?

Appendix I - Workshop online survey

Resist: Training anti-ableist caregivers to defend the rights of people with disabilities.
Location: -
Dates/Time: -

You are invited to a workshop for mothers and caregivers of children with disabilities. The workshop will work cooperatively in two groups on July 8th and 9th to first actively listen to the demands of care and then collectively build possible solutions and referrals to combat the demands brought by caregivers.

The workshop is part of a joint project by [local network], Black Lives with Disabilities Matter (VNDI) and the University of York in the UK, which aims to understand how support networks empower mothers/carers and people with disabilities by facilitating access to information about disability rights, anti-ableism, anti-sexism and anti-racism. The project aims to develop practical interventions that centre the intersecting forms of discrimination experienced by people with disabilities and women carers in marginalised and racialised communities. We would like to understand how support networks of mothers and people with disabilities can provide alternatives to medicalised narratives of disability and related support, services and treatments that can ensure dignified and quality lives.

Please note that if you choose to attend the workshop, a researcher from the project team, Lauren Avery from the University of York in the UK, will be present. You will also be invited to participate in an optional group interview during the workshop as part of the research. You do not need to attend the group interview to participate in the workshop.

If you do not wish to participate in the research, but would like to receive information about future similar workshops that do not involve research participation, please contact Luciana Viegas – VNDI – [contact] or [local contact]

You can read the participant information sheet here [link].

Workshop registration

Contact

1. Name:

2. E-mail:
3. Telephone:
4. Network affiliation (if any):

Accessibility

5. Do you have any accessibility needs to participate in the workshop?
    - I don't have
    - I need to take care of my son/daughter during the workshop
    - I need simple language
    - I need audio description
    - I need LIBRAS interpretation
    - I need documents in Braille
    - I need something else (please provide details):

Authorization to participate in the project

To participate in the workshop, you need to give your authorization to participate in the research project.

By participating in the project, I..

1. I confirm that I have read and understood the information leaflet explaining the research project above.
2. I understand how to contact the researcher if I have any questions about the research.
3. I understand that participating in the workshop means that I am agreeing to be observed as part of the research.
4. I understand that my participation is voluntary and that I am free to withdraw at any time, without justification, up to three months after my participation in the project.
5. In addition to participating in the workshop, I am pleased that the researcher asked if I would like to participate in a focus group or interview about how I access support related to my child's disability.
6. I understand what information will be recorded regarding my participation and how that information will be collected.
7. I understand how this information will be used in the project, who will have access to it, and what the research will be used for once it is completed.
8. I agree that my data may be used by the principal investigator as part of his/her doctoral thesis, publications and other academic outputs.

9. I understand that a pseudonym (fake name) will be used and anonymity procedures will be followed appropriately.
10. I understand that the organization I am a member of or work for may be named in the project.
11. I give permission for the information I provide to be deposited in the University's online research data repository so that it can be used for future research and learning.

Participant Survey

Thank you. You have successfully registered for the workshop.

In order for us to better understand the needs of workshop participants and plan the workshop accordingly, we ask participants to complete this short survey. We will not ask for your name, so the information you provide will remain anonymous and will only be seen by the project team. This survey is optional.

About you

1. Gender: female / male / other / I don't want to disclose
2. Self-declared race/color: black / brown / white / indigenous / yellow
3. Age:
4. State:
5. Municipality:
6. Level of education: none / primary education / secondary education / higher education
7. Do you identify as a person with a disability? yes/no
   If so, what type of disability?
   - Visual
   - Hearing
   - Intellectual / mental
   - Motor
   - Psychosocial (Autistic, neurodiverse, ADHD)
   - Multiple
   - Other
8. Your work:
   - I don't have a formal job / I'm unemployed
   - I work full time
   - I work part time
9. Your housing:

- I live in a house that I own
- I rent a house
- I live with a family member
- Other

About your family

10. Do you consider yourself to be the primary caregiver of a child with a disability? yes/no
11. Are you a single (solo) caregiver? yes/no
12. How many people do you have to care for in total?
13. How many of them are children with disabilities?
14. What is your relationship to the child with a disability that you care for? I am… Mother/father/grandmother/grandfather/sister/brother/aunt/uncle/other

About the disabled child you care for

15. His/Her Gender:
16. His/Her Age:
17. His/her self-declared race/color: black/brown/white/indigenous/yellow
18. Does he/she have a medical diagnosis of the disability? yes/no
19. Has he/she ever been denied access to a medical diagnosis of the disability? yes/no
    If so, why?
20. What type of disability does he/she have?
    - Visual
    - Auditory
    - Intellectual/mental
    - Autistic
    - Motor
    - Psychosocial (Autistic, neurodiverse, ADHD)
    - Multiple
21. Level of support needed for him/her in daily life: high / medium / low

22. the disabled child you care for go to school? Yes, full time / Yes, part time / No
    If not, why?
    What type of school? integrated / special / private / public

About your access to the services

23. You or your son/daughter/child with a disability receives

- Continuous Benefit Payment (BPC)? yes/no
- Family allowance? yes/no
- Minha Casa Minha Vida? yes/no
- Health insurance? Yes/No
- Therapies Yes/No

If so, which therapies?

24. Have you ever been denied access to
    - Continuous Benefit Payment (BPC)? yes/no
    - Family allowance? yes/no
    - Minha Casa Minha Vida? yes/no
    - Health insurance? Yes/No
    - Therapies Yes/No

About your support network

25. Do you have support from those who care for your child with a disability in daily life? yes/no

    If yes, who? Check all that apply
    - Your partner/husband/boyfriend
    - Your partner/wife/girlfriend
    - Other family member (female)
    - Other family member (male)
    - Another family member (girl)
    - Another family member (boy)
    - Another person who is not a family member but lives in the same household
    - Another person who is not a family member and does not live in the same house (neighbor or friend)
    - Professional

About your hopes for the workshop

1. Do you have any hope for this workshop?
2. Do you have any questions, concerns or topics you would like to be addressed in the workshop?

Appendix J - List of advocacy submissions & project report

1. **United Nations Special Rapporteur on Violence Against Women**

Contribution ahead of the visit of the Special Rapporteur on violence against women and girls to Brazil 31 July to 10 August 2023 (Confidential report).

2. **United Nations Committee on the Rights of the Child (CRC)**

Joint alternative report submission, contributing the List of Issues Prior to Reporting (LOIPR) for the review of Brazil, 2024 - Black and indigenous children with disabilities.

3. **The Committee on the Elimination of Discrimination Against Women (CEDAW)**

Joint alternative report submission, ahead of the review of Brazil, session 88, May 13 to 31, 2024 - Women and girls with disabilities and women caregivers from Black and indigenous communities.

4. **The United Nations Special Rapporteur on the Rights of Persons with Disabilities**

Call for Inputs: Care and support for children with disabilities within the family environment and its gendered dimensions – submission of project report.

5. Project Report (PDF via link) - Disability and Care: Resisting the lottery of access in the peripheries of Brazil