Project Report

Disability and care: resisting the lottery of access in the peripheries of Brazil

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Project Report, March 2025

Vidas Negras com Deficiência Importam (VNDI)

VNDI is a movement created by Black people, people with disabilities and especially Black people with disabilities in the search for an anti-racist and anti-ableist society. Our struggle and mobilization are for a social model that allows Black people with disabilities respect and human dignity through public policies to protect the population with disabilities, as well as guaranteeing the Convention on the Rights of Persons with Disabilities.

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1. Introduction

1.1. Executive Summary

This report examines the historical and social context of disability and care in Brazil, with emphasis on the perception of mothers and caregivers, highlighting the deep-rooted inequalities faced by people with disabilities and their mothers, particularly in peripheral areas. Brazil's history of exclusion, rooted in racist, ableist, and sexist ideologies, continues to marginalize Black people, women, and people with disabilities, with Black and poor women disproportionately assigned care roles.

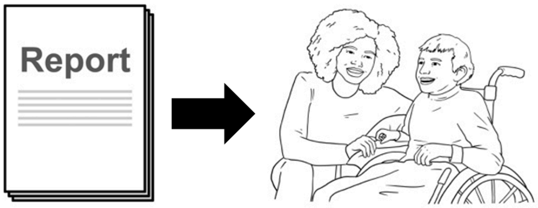
While various policies exist to support people with disabilities, inadequate care systems persist, exacerbating the oppression of both people with disabilities and women, particularly those responsible for caregiving. Father abandonment is a major issue, placing undue emotional and financial burdens on mothers. Access to information and services for mothers and people with disabilities remains inconsistent, with socioeconomic, educational, geographic, and racial factors determining availability, creating a "lottery of access" to vital support.

This report further highlights the significant barriers to healthcare, social assistance, and education faced by families with children with disabilities, particularly in peripheral areas of Brazil. Diagnosis often relies on binary, biomedical approaches, with long waiting times and bureaucratic hurdles delaying access to disability services and benefits. Post-diagnostic care is limited, leaving mothers without crucial information and emotional support.

Reliance on the public healthcare system (SUS) is linked to poorer health outcomes, while access to private healthcare exacerbates racial and geographic disparities. Additionally, families frequently struggle with a lack of information about their rights and entitlements, and bureaucratic processes often deny or inadequately provide social assistance benefits. Education access is also restricted due to discrimination and a lack of awareness of rights.

In response, community support networks have emerged, offering emotional, practical, and informational support, while some also advocate for systemic change. The report concludes with some policy recommendations.

1.2. Easy Read Summary

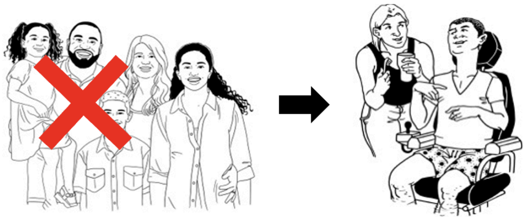


This report is about the problems people with disabilities and their mothers face in Brazil, especially in poor areas.

Many people with disabilities, Black people, and women are treated unfairly because of racism, sexism, and ableism.

Many Black women and poor women have to take care of others on their own, which makes things harder for them.

There are some policies to help people with disabilities, but they are still not good enough to let all people live good lives in their communities.

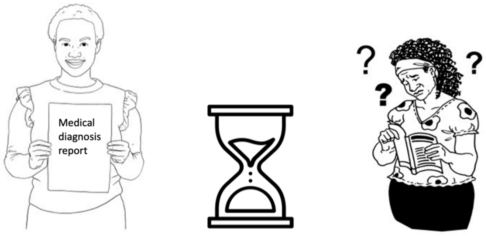


Many fathers are not involved, leaving mothers with all the responsibility.

Getting information and services is hard for many families.

Where you live, your race, and how much money you have can affect if you get help or not.

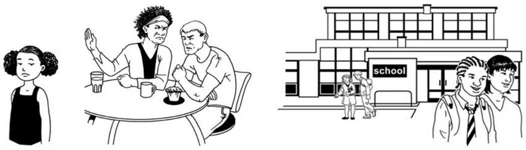
Families with children with disabilities also face problems getting healthcare, social help, and education.



Diagnoses are slow, and mothers often don’t get enough help or information.

The public health system is not always good, and private healthcare is too expensive for many people.

Families don’t always know their rights or how to get help.



Children with disabilities also face discrimination in education.

Some groups of mothers have come together to support each other. They share advice, offer help, and work to make things better.

The report ends with suggestions to improve policies and support for families.

1.4. Acknowledgements

This project report was drafted by Lauren Avery, and edited by Yara Leone da Silva, Cátia Brito and Luciana Viegas. The overall project team consisted of members of Vidas Negras com Deficiência Importam (Luciana Viegas, Cátia Brito; Gabriela Guedes; Cleciane Cruz dos Santos; Yara Leone da Silva; Maira Cavalcante) and the University of York (Lauren Avery, PhD Student; Dr João Nunes, supervisor; Professor Bryony Beresford, supervisor).

Special thanks go to Norma Johnson, Mariana Gonzaga, Vanessa Aguiar and Mariana Janeiro for their support.

The project team had different responsibilities and were involved in various aspects of the project and related advocacy activities. These included but were not limited to:, project design, data collection, organising workshops, data analysis and validation, advocacy report writing, workshop support and follow up, advocacy, monitoring and evaluation, administration, social media management, and aftercare. Many other people also generously gave us free space, cooked, provided and disseminated information, provided transport or gave their time in other ways, in support of this project.

Financial support from this project came from the University of York via an ESRC Impact Accelerator Award. Thanks go to Dr. João Nunes and the administrative team at the Department of Politics for helping the project team to apply for this award.

Finally, and most importantly, the project team wishes to thank all of the mothers, other caregivers of people with disabilities and professionals who generously gave their time, stories and emotional energy to participating in this project. This knowledge was co-created by you all and we hope that it is useful in the continued fight for justice within our communities.

2. Project Design

2.1. Project Background

The project was a continuation of a previous research and advocacy project that highlighted that Black people with disabilities and their families experience disproportionate and complex forms of intersectional discrimination in Brazil[1]. The project added evidence to existing criticism that current biomedical approach to disability diagnosis leads to barriers to diagnosis and access to support for Black people with disabilities, who are less likely to have access to health care[2] and are underrepresented in official statistics on the number of disabled people[3].

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[1] Minority Rights Group. 2021. Highlighting intersectional racial, disability and gender discrimination using international human rights mechanisms. https://minorityrights.org/programmes/highlighting-intersectional-racial-disability-and-gender-discrimination-using-international-human-rights-mechanisms/

[2] Silva, Nelma Nunes da et al. 2020. Access of the black population to health services: integrative review. Revista Brasileira de Enfermagem [online]. v. 73, n. 4. <https://doi.org/10.1590/0034-7167-2018-0834

[3] Brasil. 2010 Census. https://censo2010.ibge.gov.br/.

It is notable that this population is less likely to have access to formal work, more likely to be involved in precarious, low-paid or unemployed work[4], and more likely to be represented in institutions that segregate them from their families and communities[5] due to lack of comprehensive support and failures of existing care and disability policies. Another result of the previous project was to highlight that unpaid care of people with disabilities falls disproportionately on Black women and girls, including those who have disabilities themselves, due to the lack of a comprehensive care policy that allows people with disabilities to choose and pay for their own care[6]. Despite the persistent and exacerbated racial disparities experienced by Black people with disabilities and Black women caregivers, these concerns remain vastly under-represented in mainstream movements for the rights of people with disabilities and anti-racist movements at national and international levels.

Some key outcomes of the previous work fed into the development of this project, namely, general recognition by the United Nations Committee on the Elimination of Racial Discrimination on the intersectional forms of discrimination experienced by Black, indigenous and Quilombola people with disabilities and the burden of unpaid care work that falls disproportionately on Afrobrazilian women[7]. The continuation of this work aimed to focus on how advocacy can address neglected issues around family care and support of people with disabilities that are implicated by intersectional discrimination through inadequate state support.

While civil society organizations have engaged in disability activism to improve policies aimed at promoting the rights of people with disabilities in Brazil, support programmes, especially for families of children with disabilities, remain largely dominated by biomedical discourse.[8] As such, diagnosis of disability can only be obtained through a medical diagnosis given by a physician and support is largely directed by medical professionals in the form of treatment and therapy. As Black people with disabilities face specific barriers to accessing healthcare and disability diagnoses, much of this support also remains inaccessible. The project team recognised that the interconnected issues of unpaid care,

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[4] IBGE. 2022. https://agenciadenoticias.ibge.gov.br/agencia-noticias/2012-agencia-de-noticias/noticias/34977-desemprego-e-informalidade-sao-maiores-entre-as-pessoas-com-deficiencia

[5] BARROS, Sônia; BATISTA, Luiz Eduardo et al. Censo psicossocial dos moradores de hospitais psiquiátricos do estado de São Paulo: um olhar sob a perspectiva racial. Saúde Soc. São Paulo, v.23, n.4, p.1235-1247, 2014. https://www.scielo.br/j/sausoc/a/nF4PdVbQJz3thK9sPThVkwP/?format=pdf&lang=pt

[6] UN OHCHR. 2022. *CERD - International Convention on the Elimination of All Forms of Racial Discrimination 108 Session (14 Nov 2022 - 02 Dec 2022), Brazil Concluding Observations.* UN Treaty Bodies Database. https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/SessionDetails1.aspx?SessionID=2557&Lang=en

[7] ibid.

[8] Duttine, et al. 2020. Congenital zika syndrome—assessing the need for a family support programme in Brazil. *International Journal of Environmental Research and Public Health.* 17 (10). P.1-14.

gender and race are often left out of mainstream, white majority and global north disability rights movements, despite being a key issue within racialised and formerly colonised communities around the world.

2.2. Project Objectives

This project aimed to help civil society and community networks better understand the link between disability, race and gender discrimination that culminates in the experiences of people with disabilities and their caregivers from marginalised and racialised peripheral communities. Specifically, the project team was interested in how families of people with disabilities in peripheral areas accessed disability information, services and support, and how networks of mothers help to plug the gaps where the state fails to provide these to guarantee the rights of these populations. The project also aimed to build connections between project partners Vidas Negras com Deficiência Importam and other civil society networks and organisations and identify opportunities for joint advocacy. These organisations included organisations of people with disabilities, networks and associations of mothers or families of children with disabilities, women's organisations, and community-based NGOs.

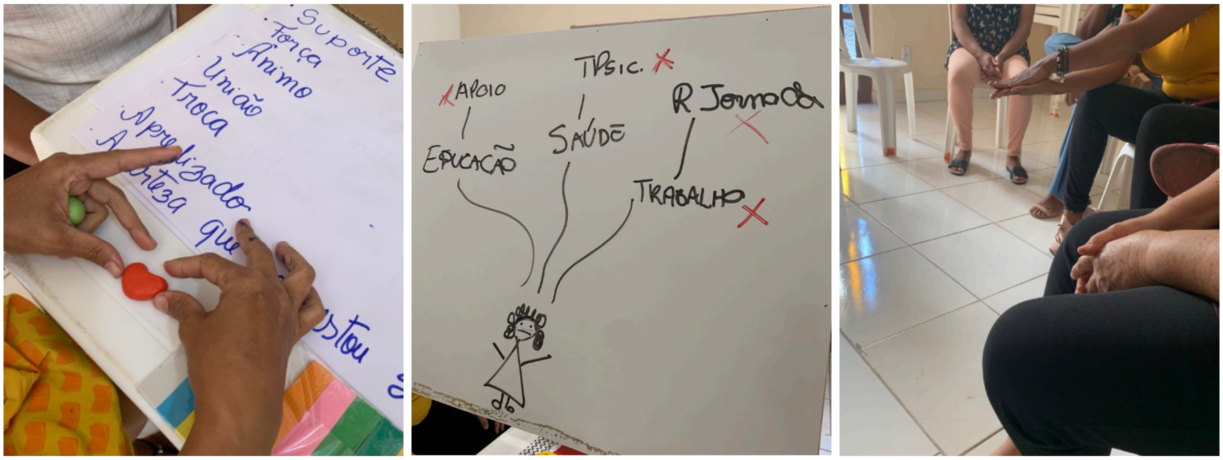
The project also aimed to conduct research to answer the following questions:

1. How and where do mothers of children with disabilities access information, services and support in peripheral areas?
2. How does this information, services and support meet the needs of children with disabilities and their mothers?
3. How do mothers create community support networks in peripheral areas?
4. How do community support networks empower mothers and help fill gaps in access to information, services and support?

Another objective of the project was to collect data that could be used for policy advocacy to improve the lives of people with disabilities and women carers in peripheral communities. Data collected during the project has been used by VNDI during advocacy during consultation on the National Care Policy and was included in various international advocacy reports, including to the United Nations Committee on the Elimination of Discrimination Against Women (CEDAW), the Committee on the Rights of the Child (CRC), the Committee on the Rights of Persons with Disabilities (CRPD), and the Special Rapporteur on Violence Against Women and Girls.

2.3. Methodology

The project took a participatory, mixed methods approach to data collection and outreach to families of children with disabilities in peripheral areas. The project adopted a participatory and mixed-methods approach to data collection and outreach to families of children with disabilities in peripheral areas. Research activities took place in workshops designed by the project team and used visual creative methods to facilitate research activities. These activities included community network presentations, mapping of access to services and support, a conversation circle and observations of training provided by civil society partners.



Photos of the workshops

Semi-structured interviews were included in the research design to gather additional information about how mothers access information, services and support, as well as the role of community information networks from external perspectives. The interviews focused on how families with children with disabilities access health, education and social care services and information in the local area, what information parents received about their child's disability and disability in general, including information about the law, and what information and support families received from community support networks.

A review of existing literature was also included in the research. This included a review of academic literature on the experiences of children with disabilities and their families, access to services for children with disabilities, women, Black, Indigenous and Quilombola populations to triangulate and give context to the research findings. A review of relevant social welfare laws, policies and programmes and their coverage and implementation was also conducted.

Ethics and Informed Consent

The project received ethical approval from the Ethics Committee for Economics, Law, Management, Politics and Sociology (ELMPS) at the University of York in the UK and the Brazilian National Commission for Research Ethics (CONEP). Participants in the online survey and workshop registration were provided with written information about the project and were asked to provide informed consent prior to the workshops. All participant and network names have been anonymised to protect the identities of participants and children.

2.4. Research Sites

The research and workshops were carried out in five municipalities in the four states of Bahia, Minas Gerais, Rio de Janeiro and São Paulo between June and October 2023.

Map of the research locations

2.5. Participant Demographics

Age, gender, race/color, and disability

Demographic and background information was collected from participants through an online survey during workshop registration. The data collected revealed that the majority of registrants (93.5%) identified as women and 89.2% as primary caregivers of a child, adolescent, or adult with a disability. The majority self-identified as Black: black (44.9% or 35 people) and brown (29.5% or 23 people); 19.2% or 15 as white; 5.1% or 4 as indigenous; and 1.28% or 1 person as Asian. Almost a quarter of registered participants also reported having a disability (23.7%), with the majority identifying as having a psychosocial disability (40.91% or 9 people) or another type of disability (31.82% or 7 people). The age range of registrants was 20 to 70 years old.

Carers

Fifty percent (50%) of respondents reported being single caregivers and approximately two-thirds reported having support from another person in the daily care they provided, compared to one-third who reported no daily support. Of those who reported receiving help from another person in the daily care of their child, 38.46% received help from a male partner; 3.85% received help from a female partner; 23.08% received help from another woman in the household; 6.41% from another man in the household; 6.41% from a girl in the household; 1.28% from another person in the household and 17.95% from another person outside the household. The majority were caring for only one person with a disability (88% or 66 individuals), but 7 individuals were caring for two people with disabilities and 2 individuals (2.67%) were caring for more than 3 people with disabilities. It was noted by participants during the workshops that many also cared for children without disabilities. The vast majority of those registered were mothers (85.53% or 65 people); with two fathers (2.63%); two aunts; one grandmother (1.32%); one uncle and 5 "others".

People with disabilities

The people with disabilities who carers were supporting were primarily identified as their children; with the majority children (under age 12), some adolescents (age 12-18) and a few adults (over 18). The majority were identified as boys or men (66.67% or 50), with 28% as girls or women; 1 other and 3 undeclared. One third identified them as black (33.33% or 24); 37.5% or 27 as brown; 27.78% or 20 as white; and one as indigenous. The vast majority (95.95%) currently had a disability diagnosis, although 21.92% stated that they had previously been denied a diagnosis. The majority of disabilities were categorized as psychosocial (including autism) at 66.22%; multiple at 14.86%; intellectual at 10.81%; other at 5.41%; motor at 1.35% and undeclared at 1.35%. 19.74% or 15 of the children were classified as being at support level 3 (highest); 61.84% or 47 as being evaluated at support level 2; and 18.42% or 14 as being evaluated at support level 1 (lowest).

Socioeconomic status

In terms of employment status, 58.4% reported that they were unemployed or not working, 14.3% worked part-time and 27.3% worked full-time. This is consistent with other research in Brazil showing mothers of people with disabilities are between 17% and 25% less likely to participate in the labour market[9]. For housing, 53.4% owned their own home, 30.1% rented, 8.2% lived with a family member and 8.2% reported another housing situation. Education levels were reported as: none, one person or 1.3%; primary education, one person or 1.3%; secondary education as 29 people or 37.66% and higher education as 46 people or 59.74%.

The survey also asked about access to benefits and services, to get an idea of the participants' socioeconomic situation and experiences with access. When reporting current

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[9] Soares et al. 2020. O efeito de filhos com deficiência intelectual na oferta de trabalho das mães no Brasil. Revista Brasileira de Estudos de População. 37. Pp. 1-22.

access, 15.1% said they had access to a private health insurance plan; 16.1% said they had access to the Bolsa Família scheme; 26.9% had access to the disability benefit (BPC); 8.6% received child support; and 28% reported that their child had access to therapies (the information did not specify the type) and 5.38% to the Minha Casa Minha Vida housing scheme. Regarding previous denial of access to services or benefits, in response to the question 'have you ever been denied access to…', 10.5% reported having been denied access to a health plan; 10.5% had been denied access to the Bolsa Família scheme; 22.1% had been denied access to the BPC; 32.6% reported having been denied access to therapies; and 15.8% were denied access to the Minha Casa Minha Vida (housing) scheme.

3. Disability, Race, Gender and Care in Brazil

3.1. Historical Context

Disability and slavery

Studying Brazilian history and the subjugation of Black and indigenous people, people with disabilities, the unemployed and children is central to fully understanding the persisting social inequalities for people with disabilities and their families in peripheral areas[10]. Despite the lack of historical documentation, there is evidence to show that people with disabilities were enslaved and that enslaved bodies were ranked based on factors like age, gender, ethnicity, and disability. For example, in Brazil, enslaved individuals' prices varied depending on these characteristics, similarly in the U.S., they were ranked by age, gender, and skillset[11].

Enslaved individuals were more vulnerable to disability due to poor living conditions, disease, and violence, yet people with disabilities were not excluded from labor. In fact, some enslaved individuals with disabilities, such as blind people in Brazil, were even preferred for certain tasks due to their increased control by enslavers[12]. Following emancipation, disabled, elderly, and children were often abandoned or institutionalized, as they were seen as unproductive and dependent on slavery[13]. The ranking of worth based on ability and disability was central to the slavery system, deeply influencing concepts of disability in Brazil and beyond, rooted in eugenics, racism, and colonialism.

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[10] Lobo, L. 2008. Os infames da história: pobres, escravos e deficientes no Brasil. Rio de Janeiro: Lamparina.

[11] Williamson & Cain, 2024. Measuring Slavery in 2020 dollars. Measuring Worth website. Accessed from: www.measuringworth.com/slavery.php.

[12] Oliveira, 2023. Trabalho para escravizados cegos: modos de exploração e resistência no século XIX. Revista Eletrônica Trilhas da História. 12(24). Pp. 261-278.

[13] Downs, 2008. The Continuation of Slavery: The Experience of Disabled Slaves during Emancipation. Disability Studies Quarterly. 28(3). Accessed from: https://dsq-sds.org/index.php/dsq/article/view/112/112

19th Century onwards

In 19th-century Brazil, Black people, women, and people with disabilities were excluded from citizenship through racist, ableist, and sexist ideologies. Even after abolition in 1888, former enslaved people and their descendants remained marginalized, lacking access to land, education, and employment. Early 20th-century policies linked racism and ableism, promoting eugenics and discouraging interracial and disabled unions[14].

Brazil's military dictatorship (1964–1985) suppressed political opposition and curtailed rights, including those of people with disabilities. During this period, disability was largely ignored in public policy, and many people with disabilities were institutionalized in poor conditions. Following the dictatorship, the **Development and Democracy** period (1985–2000) focused on restoring democratic rights and addressing social issues, including the rights of marginalized groups, leading to the creation of the **Unified Health System (SUS)** in 1988. SUS aimed to provide universal healthcare, including for people with disabilities, ensuring better access to services, rehabilitation, and support.

In the early 2000s, the **psychiatric reform** began, focusing on deinstitutionalizing people with psychosocial disabilities and moving away from asylums toward community-based care. This was part of broader efforts to integrate people with disabilities into society, providing rights and opportunities for inclusion. The 2001 Psychiatric Reform Law[15] emphasized mental health treatment in community settings, promoting autonomy and reducing the harmful effects of institutionalization. These changes reflected a shift towards recognizing and respecting the rights of people with disabilities in Brazil, ensuring they could access healthcare and social services while participating fully in society.

Black women, care and people with disabilities

Black women's roles during slavery intersected with disability and care. They were responsible for domestic labor and childrearing for slave owners, and often forced to neglect their own children, particularly those with disabilities. These children were often considered "useless" by slave owners and subjected to neglect or invasive treatments[16].

The double exploitation of Black women continued after abolition. Today, Black women in Brazil still make up most of the domestic and care workforce, earning less than the minimum wage and facing precarious conditions. The 2023 National Household Sample Survey (Pnad) showed that 66% of domestic workers were Black women, who earned

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[14] French & Stepan, 1993. "The Hour of Eugenics": Race, Gender, and Nation in Latin America. The Western Historical Quarterly. 24(4). pp. 565.

[15] Brasil. 2001. Lei No.10.216, de 6 de abril de 2001. Presidência da República, Casa Civil. https://www.planalto.gov.br/ccivil_03/leis/leis_2001/l10216.htm

[16] Barclay, 2014.Mothering the "Useless": Black Motherhood, Disability, and Slavery. Women, Gender, and Families of Color. 2(2). Pp. 115-140.

significantly less than non-Black workers, often experiencing poverty[17]. This ongoing exploitation reflects the legacy of slavery and systemic marginalization that impacts on peripheral communities in modern-day Brazil.

Unpaid care work provided by women, especially Black and poor women in peripheral areas, is often overlooked in official statistics, particularly for family members with disabilities. These women are more likely to perform this work due to socioeconomic disparities and the inability to afford professional care. The exploitation of Black and peripheral women is perpetuated by the lack of policies designed to protect and promote the human rights of persons with disabilities, especially to choose and direct their own care. Disability and care are therefore presented as family issues, that responsibilize women and girls to provide care, many of whom also have disabilities themselves.

3.2. Current Policy Landscape

Brazil has implemented several policies to support and protect the rights of people with disabilities and their families:

Brazil has signed and ratified the **United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006).**

The **Brazilian Constitution (1988)** guarantees equality and non-discrimination, explicitly ensuring rights for people with disabilities.

The **Statute of the Person with Disabilities (2015)**, also known as the **Brazilian Inclusion Law**, provides comprehensive protections, including access to education, healthcare, transportation, and employment. It mandates reasonable accommodations and accessibility in public spaces.

The **National Policy on the Rights of Persons with Disabilities (2004)** promotes social inclusion and the integration of disabled individuals into society.

Brazil's **Law of Education for People with Disabilities (2008)**, part of the broader **National Education Guidelines and Framework Law**, ensures inclusive education for students with disabilities at all educational levels.

Brazil has several social welfare policies designed to support people with disabilities:

The **Continuous Cash Benefit (BPC)** provides financial assistance to low-income individuals with disabilities who are unable to support themselves. However, as of 2015,

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[17] DIEESE, 2024. AS DIFICULDADES DAS TRABALHADORAS CULDA- DOMÉSTICAS NO MERCADO DE TRABALHO DES DAS E NA CHEFIA DA FAMÍLIA. Boletim Especial - 30 de abril de 2024. São Paulo.

more than 70% of children with disabilities were not receiving the BPC, because of the low-income threshold to attain it[18].

The **National Health System (SUS)** ensures access to free medical care, including specialized treatments, therapies, and medications for people with disabilities. Additionally, the **Social Assistance Policy** focuses on improving social inclusion, offering services like rehabilitation, vocational training, and support for caregivers.

The **Quota Law (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.

At the time of writing, there is **no care policy that provides financial support to people with disabilities who rely on care or support**. As a result, there is a continued reliance on unpaid family care, which is justified by a historic, yet ongoing 'naturalization' of care as a responsibility of women and girls, and the depoliticization of disability as a family matter[19]. This reduces people with disabilities to passive recipients of charity rather than rights holders to whom the state has a responsibility and reduces the choices of themselves and their family members about who provides their care and support[20]. Markers of race/ethnicity, socioeconomic status, poverty, disability and gender are also relevant here, as they define who is able to afford to outsource private care and which families are most made most vulnerable as policies and support do not reach them.

There are ongoing discussions about the introduction of a **National Care Policy (Política Nacional de Cuidados (PNaC))**, which is currently under a period of public consultation. There is an urgent need for new policies to address the needs of those in peripheral areas and provide adequate support to promote the human rights and dignity of all people with disabilities and their families.

3.3. Negligent Fatherhood

Whilst the focus of this study was on mothers, the serious impacts of what we term, *negligent fatherhood*, including ableism perpetuated by fathers, stands out as an important

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[18] Wapling, Schjoedt and Kidd. 2020. Social Protection and Disability in Brazil. Accessed from: https://www.developmentpathways.co.uk/wp-content/uploads/2020/02/Social-Protection-and-Disability-in-Brazil-1.pdf

[19] Moraes, P. 2019. Deficiência e cuidado: implicações para as políticas públicas. O Social em Questão. 43. Pp. 325-348.

[20] McLaughlin et al. 2008. Families raising disabled children: Enabling care and social justice. Basingstoke: Palgrave Macmillan.

factor influencing their experiences as well as the wellbeing of children with disabilities that the authors highlight as an issue for further research.

The majority of caregivers for children with disabilities are mothers, largely due to high rates of paternal abandonment and the gendered nature of care work perpetuated by societal norms and lack of progressive policies. A 2012 study by Instituto Baresi found that approximately 78% of children with disabilities were abandoned by their fathers before the age of five[21]. Other research indicates that the number of households with single mothers increased by 17.8%, from 9.6 million to 11.3 million between 2012 and 2022, with high prevalence of Black and brown single mothers[22]. While official data disaggregated is lacking, some mothers of children with disabilities interviewed in this study estimated paternal abandonment rates in peripheral families to be as high as 90%.

Several mothers described how their children's fathers had not accepted the diagnosis of their child, or rejected the child after a diagnosis, leaving mothers as the sole provider for the family. One mother 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.'***

The impacts of paternal abandonment on families can have serious financial and emotional consequences for mothers and children. Despite parents being obliged by law to provide financial support for their children via the pensão alimentícia, some mothers reported difficulties in getting fathers to pay, including through the courts.

Even when fathers did not abandon their families, mothers reported that fathers often did very little to help in the everyday care of children with disabilities. A social worker in São Paulo also observed the low rates of participation of fathers in their children's lives, ***'Do I have participative fathers? I have. But I can count on one hand...the rest are women.'***

There were also a few reports of domestic abuse towards mothers by fathers, who blamed them for the child's disability. This blame has been linked in previous studies to fathers'

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[21] Ministério Público do Pernambuco. 2015. Centro de Apoio Operacional de Defesa da Educação. Accessed from: https://cao.mppe.mp.br/documents/d/caos/nota-tecnica-n-003-2022-educacao-inclusiva-intersetorialidade-de-politicas-publicas?download=true

[22] Getúlio Vargas Foundation (FGV). 2023. Mães solo no mercado de trabalho crescem 1,7 milhão em dez anos. Getúlio Vargas Foundation (FGV) website. https://portal.fgv.br/artigos/maes-solo-mercado-trabalho-crescem-17-milhao-dez-anos

inability to accept a ‘non-perfect’ child and the high rates of fathers abandoning mothers of children with disabilities and rare diseases in Brazil[23][24].

4. A Lottery of Access

The project aimed to discover how caregivers of children with disabilities access information and support in peripheral areas and how this meets the needs of families. It was concluded that access to information, rights and services was experienced as a lottery, meaning access was not guaranteed and unpredictable, defined by socioeconomic, educational, geographic and social factors that were often linked to race/ethnicity and peripheral identity. Lack of access to information about disability and rights was an overarching and recurring theme across all three main areas of interest of the study; health, education and social care. It was found that in health, education and social care systems, disability was often framed in a biomedical way which pathologized disability rather than adopting a biopsychosocial approach in line with the Brazilian Inclusion Law and the Convention on the Rights of Persons with Disabilities (CRPD).

While there is no doubt that good practice exists, most families involved in the study did not receive comprehensive information about their children’s rights or information about services in their local area and how to access them, due to a lack of coordination within the health, social care and education systems and the dominance of a biomedical approach to disability within the systems. There were several implications for this lack of access to information about disability rights, which are discussed in the following two sections.

4.1. Healthcare

Diagnosis

Disability diagnosis in Brazil at the time of data collection took a biomedical, binary (disabled or not disabled) approach. This has been recognised by disability rights activists and the Brazilian government as problematic, ‘*generating low focus of public policy and preventing those with greater restrictions on participation in society, who are more vulnerable, from being in fact reached according to their needs*.'[25] This approach can mean that whilst

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[23] Albuquerque et al., 2019. Access to healthcare for children with Congenital Zika Syndrome in Brazil: Perspectives of mothers and health professionals. Health Policy and Planning. 34(7). P.499-507.

[24] Ministério Público do Pernambuco, 2015. Centro de Apoio Operacional de Defesa da Educação. https://cao.mppe.mp.br/documents/d/caos/nota-tecnica-n-003-2022-educacao-inclusiva-intersetorialidade-de-politicas-publicas?download=true

[25] Ministerio da Mulher da Família e dos Direitos Humanos; Secretaria Nacional dos Direitos das Pessoas com Deficiência. 2021. RELATÓRIO DE ANÁLISE EX ANTE DA IMPLANTAÇÃO DO SISTEMA UNIFICADO DA AVALIAÇÃO BIOPSICOSSOCIAL DA DEFICIÊNCIA EXPEDIENTE. p. 33.

children remain undiagnosed, access to things like healthcare, medication, therapies, disability benefits, and assistive devices, remain out of reach.

Furthermore, Brazil's fragmented disability evaluation system adds further barriers to diagnosis. Of thirty-four policies, benefits and services for people with disabilities and carers, thirty have their own separate method of evaluating or diagnosing disability[26], meaning different evaluations and the need for periodic reevaluation can allow access to some benefits and services whilst barring access to others simultaneously.

Almost one quarter of those who filled out the participant 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 children, the process was slow and bureaucratic and the period without diagnosis created delays in access to other services and benefits. For example, mothers report spending a lot of time trying to find a healthcare centre that was equipped with the right expertise and correct diagnostic testing to provide a medical disability report [PT: *Laudo Médico para PCD*]. A mother living in Favela de Manguinhos, Rio de Janeiro explained that, ***'most autistic people [here] are not diagnosed... Because they keep making the mother a shuttlecock.'***

Access to healthcare services in Brazil are profoundly marked by racial, socioeconomic, and geographic disparities, indicating that access to a medical disability diagnosis is also divided along racial lines, with Black, peripheral communities most likely to experience barriers to diagnosis. Results from the 77 online survey respondents showed there was a racial discrepancy in those reporting experience of denial of a diagnosis, with 27% of Black children experiencing denial at some point in comparison to 10% white children.

Waiting lists and bureaucracy

High levels of bureaucracy linked to long waiting lists were reported as a consistent barrier to diagnosis and other types of healthcare. The 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)].

> ***'If you stay in regulation [SISREG], you die'*** *- NGO worker, Bahia.*

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 401% between 2023 and 2024[27]. The longest wait

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[26] ibid.

[27] Grinberg & Bustamante, 2024. Além da morte na UPA: Rio tem 427 mil pessoas na fila por uma consulta, uma cirurgia ou um exame. O Globo website. https://oglobo.globo.com/rio/noticia/2024/12/17/rio-tem-427-mil-pessoas-na-fila-por-uma-consulta-cirurgia-ou-exame.ghtml.

times published in an analysis of the report by O Globo, were for initial appointments for paediatric intellectual rehabilitation[28], on average 304 days in 2023 and 251 days in 2024.

Findings from this study support the SISREG study, with mothers and professionals across all research sites noted that the longest waiting lists were for an initial appointment with a neuro pediatric doctor after having been referred from a primary health unit [*PT: Unidade Básica da Saúde (UBS)]*. For example, a city councillor in São Paulo noted that waiting lists in the region could extend ***'three months, six months, a year and even cases that were for years.'*** From a mother'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.'***

Post-diagnostic care & support

A lack of post-diagnostic care and support that helped mothers to understand their child's diagnosis and needs from a rights-based and holistic perspective also impacted mothers' and children's wellbeing. Most of the mothers involved in the study reported never having received any sort of professional psychological support during the post-diagnostic phase and experienced difficulties in adjusting and accepting the diagnosis or their child's disability. A social worker at an 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 become 'normal'.

Similarly, a SUS psychologist in Bahia noted that mothers who she worked with who did not understand their child's diagnosis can ***'have a very distorted view... a very catastrophic vision that, "ah, my son has this, so he will never improve, he will never progress"'.*** Previous research shows links between lack of support, high parental stress and negative wellbeing outcomes for children with disabilities[29]. Yet demand on psychosocial support services within the SUS is extremely high, leaving many families without this essential post-diagnostic support[30].

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[28] includes referral to multidisciplinary teams including healthcare staff such as neuro paediatricians, psychiatrists, paediatricians, occupational therapists, nutritionists and physiotherapists as well as social workers.

[29] Bérgamo & Bazon, 2011; de Barros, Deslandes, & Bastos, 2016; L. C. Moreira & Mouro, 2021

[30] V. C. R. da Silva & Silva, 2022. A IMPORTÂNCIA DO SUPORTE PSICOSSOCIAL ÀS MÃES DE CRIANÇAS COM TRANSTORNOS DO ESPECTRO AUTISTA (TEA). Universidade Federal de Pernambuco: Departamento de Políticas e Gestão da Educação.

Reliance on the SUS

For 75% of conversation circle participants, private healthcare, to be discussed in the following subsection, remained unaffordable, meaning the SUS was the only option to access healthcare. 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[31]. The long-term chronic underfunding and dismantling of the SUS[32][33] and other public services therefore exacerbate inequalities experienced by communities in peripheral areas and regional disparities[34]. As one mother in Rio de Janeiro put it, ***'we are at the mercy of the SUS.'***

The results showed that access to the SUS was marked by poor provision, overstretched services, medical negligence, medical racism and delays in accessing healthcare. In some cases, mothers attributed delayed access to maternity care or postnatal care to causing their children's disabilities. One Black mother in Bahia reported, ***'the intellectual disability was caused... I did all the prenatal care, but when I got there, they took a long time to see me and there was no more fluid, he almost died in my hands.'***

Similarly, at a clinic for people with disabilities in Rio de Janeiro staff noted that many of the Black children they attended had acquired complex disabilities during or after birth linked to poor healthcare attendance in the favelas where their families lived. 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.[35] Whilst research on these links is scarce in Brazil, between 2015 and 2022, maternal death risk was twice as high for Black women than white women in Brazil[36] and rates of obstetric violence are also higher amongst Black mothers and those with lower levels of education.[37]

Whilst many mothers reported supportive and caring attitudes from healthcare, education and social work professionals, others described ableist attitudes that reduced their

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[31] Ministério da Saúde. 2017. Política Nacional de Saúde Integral da População Negra. Pp. 1-46.

[32] Mendes, A. 2013. The long battle for SUS funding. Saude e Sociedade. 22(4). Pp. 987-993.

[33] Souza, D. 2020. O subfinanciamento do sistema único de saúde e seus rebatimentos no enfrentamento da covid-19. Physis. 30(3). Pp. 1-6.

[34] Marques, G. 2019. DESCENTRALIZAÇÃO E SUBFINANCIAMENTO NO SUS: IMPACTOS NA EQUIDADE E ACESSO À SAÚDE NO BRASIL (1998-2018). Revista Multidisciplinar. 19(July/Dec). Pp. 278-291.

[35] Lassi, Majeed, Rashid, Yakoob, & Bhutta, 2013. The interconnections between maternal and newborn health-evidence and implications for policy. Journal of Maternal-Fetal and Neonatal Medicine. 26(1). Pp. 3-53.

[36] Maria do Carmo Leal, Granado, Bittencourt, Esteves, & Caetano, 2023. Nascer no Brasil II: pesquisa nacional sobre aborto, parto e nascimento 2022-2023. Rio de Janeiro.

[37] Graell, Morganti, Novo, Braga, & Carioca, 2024. Mães negras e com baixa escolaridade são maiores vítimas em casos de violência obstétrica, diz pesquisa da Fiocruz. O Globo website. Rio de Janeiro. https://g1.globo.com/rj/rio-de-janeiro/noticia/2024/07/08/maes-negras-e-com-baixa-escolaridade-sao-maiores-vitimas-em-casos-de-violencia-obstetrica-diz-pesquisa-da-fiocruz.ghtml.

children’s lives to medicalised and ableist notions of abnormality or tragedy. In Rio de Janeiro, one mother described how when she had given birth six months prematurely to a daughter who had 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’.***

High Complexity Services

Access to complex health services was identified as an issue that was particularly relevant to the children of participants in the study, as they were more likely to rely on these services[38]. The theme of lack of service provision reported by participants is consistent with large-scale research across Brazil 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 dominated by the majority white higher income population[39]. Interviews highlighted that accessing essential services like physiotherapy and specialized consultations in peripheral areas is fraught with challenges, leading to uneven and unpredictable access to healthcare for both mothers and their children.

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. A mother in Minas Gerais explained how her son with CZS was unable to access all the therapies that he was recommended due to the high 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.’***

Impacts of lack of access to high complexity health services for children with CZS could also result in serious health decline and mortality. 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 underlines the extreme end of potential consequences of lack of access to high complexity healthcare due to the failure of the state to guarantee universal access in line with Article 2 of Law 8.080 on the SUS[40].

Private Healthcare

Healthcare can be accessed via a two-tier system in Brazil, consisting of the SUS and private healthcare plans, which have low-cost options available. Although private healthcare is not

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[38] High complexity health services include intensive therapies such as physiotherapy, cancer treatments and specialised surgeries.

[39] Tomasiello et al., 2021. Desigualdades raciais e de renda no acesso à saúde nas cidades brasileiras. Instituto de Pesquisa Econômica Aplicada (IPEA). 1. pp. 1-38.

[40] Brazil. 1990. LEI Nº 8.080, DE 19 DE SETEMBRO DE 1990. Accessed: https://www.planalto.gov.br/ccivil_03/leis/l8080.htm

superior, healthcare plans offer easier access to some services, facilities, professionals and technologies[41] and is correlated with greater utilization of healthcare services overall[42].

Research indicates widespread racial and geographic disparities in access to private healthcare; the low levels of income of the Black population makes them less likely to be able to afford private healthcare insurance than the white population[43]. This research was consistent with the low coverage of participants by private healthcare in this study; **only 15% of participants had access to a health plan and many cited cost as a barrier**. Even for those who did have 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 complex disabilities such as Congenital Zika Syndrome (CZS), for whom medical intervention and therapy is often life-preserving. A mother-leader of an NGO for children with CZS in Bahia explained how her healthcare plan has provided her daughter, who has CZS, with access to respiratory therapy everyday, which she attributed to her lack of hospitalisation. In comparison, she reflected how the other children with CZS part of the same network who did not have access to private healthcare that covered these therapies have higher rates of hospitalization and mortality.

> ***'the difference is access, right? You can clearly see the difference in the children who do...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 hospitalized. And there we see several children being hospitalized all the time. Because it's not a service that you can easily find, anywhere.'*** - mother, Bahia.

It is proposed, therefore, that negative health outcomes including mortality for children from lower socioeconomic backgrounds, living in peripheral areas and Black, is directly related to access to certain healthcare services through healthcare plans and lack of access via the SUS.

Other research indicates that dual use of the public and private healthcare systems, whilst common, results in complications because the two systems are not comprehensively linked and so referral and communication between systems can be bureaucratic and slow, with

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[41] Silva B, Hens N, Gusso G, Lagaert S, Macinko J, Willems S. Dual Use of Public and Private Health Care Services in Brazil. Int J Environ Res Public Health. 2022 Feb 6;19(3):1829. doi: 10.3390/ijerph19031829. PMID: 35162852; PMCID: PMC8835064.

[42] Coube M, Nikoloski Z, Mrejen M, Mossialos E. Persistent inequalities in health care services utilisation in Brazil (1998-2019). Int J Equity Health. 2023 Feb 2;22(1):25. doi: 10.1186/s12939-023-01828-3. PMID: 36732749; PMCID: PMC9893569.

[43] Ministério da Saúde. 2017. Política Nacional de Saúde Integral da População Negra. Pp. 1-46.

implications for health outcomes[44]. For some mothers who took part in this study, healthcare plans had helped them to secure therapies for their children that had been denied via the SUS, but only after long delays and a bureaucratic battle with the healthcare plan provider to get them to cover those therapies. This had left some families paying out of pocket for therapies that they couldn't get either via the SUS or on their healthcare plan, and others without. One mother in São Paulo explained how she ***'spent two years paying the speech therapist that didn't comply with the health insurance'*** in order to secure access for her daughter.

Participants also claimed that private healthcare use could lead to denial of access to SUS services. Mothers in Bahia suspected that their children were denied access to healthcare services in the SUS because their children's Autism diagnoses had been obtained via the private system. One mother observed, ***'it's because the report is from Hapvida[45]...if you pay for a plan, even if it's a R$140 plan...they deny assistance because of this, seeing the [private healthcare] report.'***

4.2. Social Assistance

Lack of information on rights & benefits

Because disability diagnosis is usually dealt with exclusively in a healthcare setting, participants reported that information provided to mothers is often limited to a medical report and guides to therapeutic interventions. Many mothers reported that they had never been referred to a social worker, nor been provided with any information about the rights and entitlements that children with disabilities or carers have as per Brazilian law. A SUS psychologist who worked with mothers of children with disabilities further noted that this lack of knowledge impacted 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.'*** Yet, despite the distress that mothers reported, the majority had never been able to access any psychosocial support due to high demand on services.

Some participants noted a difference in access to information across socioeconomic divides. For example the leader of a network for children with disabilities that spanned two São Paulo municipalities noted, ***'in [municipality 1] the person says, 'that's the law here' and tells you... that it is their right, they will go after it and they will look for a lawyer... [in municipality 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".'***

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[44] Silva B, Hens N, Gusso G, Lagaert S, Macinko J, Willems S. Dual Use of Public and Private Health Care Services in Brazil. Int J Environ Res Public Health. 2022 Feb 6;19(3):1829. doi: 10.3390/ijerph19031829. PMID: 35162852; PMCID: PMC8835064.

[45] Hapvida is a private healthcare plan provider in Brazil.

The divide in access to information about rights and services was also reiterated by mothers during a conversation circle in Bahia, who noted ***'the policy means that peripheral mothers do not have the knowledge that other mothers who are not peripheral have...we are deficient in information.'*** She further observed that for mothers in peripheral areas, rights-based knowledge is made inaccessible and therefore often never becomes known to them, creating ***'an environment where we can't talk about policies...there is no way to'.*** It is therefore suggested that 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.

Access to benefits

Denial of access to benefits and social assistance services was a common theme and participants spent a long time talking about negative experiences that they had during processes of proving their eligibility via disability evaluations. In the participant survey, 15.8% had been denied access to Minha Casa Minha Vida, and 10.5% had been denied access to Bolsa Família. Only 26.9% had children receiving the main disability benefit, the Benefício Prestação Continuada (BPC), though 22.1% reported experiencing denial of the BPC in the past. Of those who had access to the BPC, they reported they had managed to get access after a long bureaucratic process, often being denied multiple times and sometimes resorting to judicial processes.

National level research shows that the **average wait time for a disability evaluation for the BPC increased from 1.25 months in 2016 to 6.61 months in 2021**[46]. 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[47]. This indicates that **at least half of all eligible BPC claims are denied via the regular administrative process**. This was consistent with the reports by many participants in this study who noted that they had only been successful as they went through a legal process to get access to the BPC. For others, judicial processes were inaccessible and so they remained without access, despite the possibility that they were eligible.

The implications of denied access to social assistance benefits was the exacerbation of financial precarity for families. Some mothers who took part in the research were not eligible for the BPC because they earnt above the threshold, which is criticized as being extremely low[48]. Therefore, families who are left without support mostly belong to Brazil's

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[46] Ministério da Mulher da Família e dos Direitos Humanos; Secretaria Nacional dos Direitos das Pessoas com Deficiência, 2021.

[47] Ibid.

[48] 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.

lower middle-income group[49]. Mothers across all research sites, with and without access to social assistance benefits 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 or fundraising for assistive devices like orthosis or wheelchairs because they were unable to access these via the SUS.

One mother in São Paulo has resorted to fundraising at her daughter's school to buy her wheelchair. She said, '***what were we going to do? Because a wheelchair costs around R$10,000, right? Apart from the maintenance that has to be done on the chair, it is not cheap either.'*** Despite being a guarantee of the law for children to be able to get wheelchairs and other assistive devices for free on the SUS, in practice, this was reported as not possible by many mothers.

The BPC is an individual benefit that is not designed to cover the loss of income related to caring activities. Yet for most families the BPC must cover one person's loss of income and two or more people's ongoings and additional costs associated with a disability on only one minimum wage salary, hence keeping the family in relative poverty[50]. One mother, part of a network in Minas Gerais for mothers of children with CZS, noted that despite receiving the BPC and other social assistance benefits, mothers 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 friends, family and local NGOs to cover their costs and provide food and necessities for their children**. Although there is a proposed Bill (4,680/2024) to increase the BPC allowance by 25%[51] for beneficiaries who rely on daily assistance from a carer, it has been acknowledged that this amount would still not remunerate the full cost of a carer, which is valued at around four times the amount of the proposed increase, which may or may not be passed by Congress [52].

4.3. Education

Across all research sites mothers and professionals described how children with disabilities were denied school places and faced exclusion and bullying at mainstream schools because

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[49] Soares, S., and Souza, P.H.G.F (2012). No Child Left Without: A Universal Benefit for Children in Brazil. No.27. International Policy Centre for Inclusive Growth Research Brief: Brazil, Brasilia.

[50] Medeiros, Diniz, & Squinca, 2015. Cash Benefits To Disabled Persons in Brazil: an Analysis of Bpc-Continuous Cash Benefit Programme. Texto para Discussão. 1184. Pp. 7-31.

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

[52] Agência Senado, 2025. Projeto garante acréscimo de 25% no BPC para quem precisa de cuidador — Senado Notícias. Brazilian Senate website. https://www12.senado.leg.br/noticias/materias/2025/01/15/projeto-garante-acrescimo-de-25-no-bpc-para-quem-precisa-de-cuidador.

of lack of training on inclusive education practices, lack of resources and ableist attitudes from education professionals. Some mothers reported that they had removed their children from schools and placed them in special schools, either because of bullying, lack of inclusive classroom practices or denial of a place.

In the view of one mother whose son attended an APAE school in São Paulo, ***'the public school system is not inclusive, it doesn't teach anything... here [APAE] welcomed our children... My son went to the public school system...What happened? They beat him."*** Despite specialized clinic-schools like APAE being criticized for taking a biomedical and segregated approach, many parents were left without a choice when children faced discrimination, exclusion and bullying in mainstream settings.

Furthermore, the lack of information parents receive about their rights and inclusive education disempowers them from being able to contest these instances of discrimination. A SUS psychologist said that most parents were unaware of their right to inclusive education and processes to appeal against denial of school places under the Brazilian Law of Inclusion[53] which created vulnerability to discrimination. In her experience, ***'many mothers, because that institution denies [a school place], they don't know that they have the right to appeal. To appeal and say, "no, I'm going to go to court because my son has the right, right?" So, mothers leave it at that because they don't have knowledge about it.'***

The private sector psychologist further pointed out that even service professionals were left without knowledge about 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.'*** Education was therefore an ongoing issue for many participants across all research sites, which could also impact a mother's ability to enter and stay in the job market, as well as impacting their children's and their own mental health.

5. Resistance: Community Care Networks

In reaction to the lottery of access that families in the peripheries experience as outlined in the previous sections, many community support networks have been established in these communities, mainly by mothers of children with disabilities, aiming to provide social support to other families facing similar difficulties. Networks included in this study were made up mainly of mothers, and included networks aimed at one specific disability type (e.g. Autism) as well as networks for families of children with various disabilities. Most networks in the study were registered as private associations with the Brazilian National Registry of Legal Entities (CNPJ), though registration didn't determine their level of activity or access to physical space. Some networks remained virtual, especially post-Covid-19,

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[53] BRASIL. 2015. Lei Brasileira de Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência). Lei nº 13.146. Brasília-DF.

while some functioned like NGOs, offering social, healthcare, or educational services through employed professionals or local volunteers, funded by donations.

Similar research on parents of children with disabilities in Brazil also shows that many other parents associations and networks also formed when parents of Autistic children and children with multiple or learning disabilities met at clinics or were introduced by physicians during the 1980s[54] and also during and after the Zika epidemic of 2015 and 2016 [55][56]. Some key functions of Mothers' networks discovered during the study were emotional support, instrumental support, informational support and facilitation of collective action towards systems change. These functions will be elaborated on below.

Emotional support

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[57] and as a key function of social support provided by mothers' networks. Research on peer support groups for parent-carers in Brazil and other settings also show that these can provide essential support and improve mental health, wellbeing, coping and empowerment outcomes in the short and longer term.[58][59][60]

Through connecting mothers, networks provided members with a sense of belonging, connectedness and shared struggle, which was seen as an essential part of the emotional support networks facilitated. 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. Participants from a network of mothers of Autistic children in Bahia, presented their network as a drawing of a tree:

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[54] Cavalcante, 2003. Pessoas muito especiais: a construção social do portador de deficiência e a reinvenção da família. Tese. Rio de Janeiro: Fundação Oswaldo Cruz Escola Nacional de Saúde Pública Curso de Doutorado em Saúde Pública.

[55] Matos & Silva, 2020. "Nada sobre nós sem nós": associativismo, deficiência e pesquisa científica na Síndrome Congênita do Zika Vírus. Ilha. 22(2). Pp. 132-167.

[56] Valentes et al. 2024. Associations of mothers and family members affected by congenital Zika virus syndrome: profile and main related discussions. Physis: Revista de Saúde Coletiva. 34. Pp. 1-26.

[57] Jacobson, 1986. Types and timing of social support. Journal of health and social behavior. 27(3). Pp. 250-264.

[58] Bray et al. 2017. Parent-to-parent peer support for parents of children with a disability: A mixed method study. Patient Education and Counseling. 100(8). Pp. 1537-1543.

[59] Duttine et al. 2020. Juntos: A support program for families impacted by congenital zika syndrome in Brazil. Global Health Science and Practice. 8(4).Pp.846-857.

[60] Lancaster et al. 2024. Exploring long-term outcomes of a peer support programme for parents* of children with disability in Australia. Child: Care, Health and Development. 50(2).

> ***‘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.’***

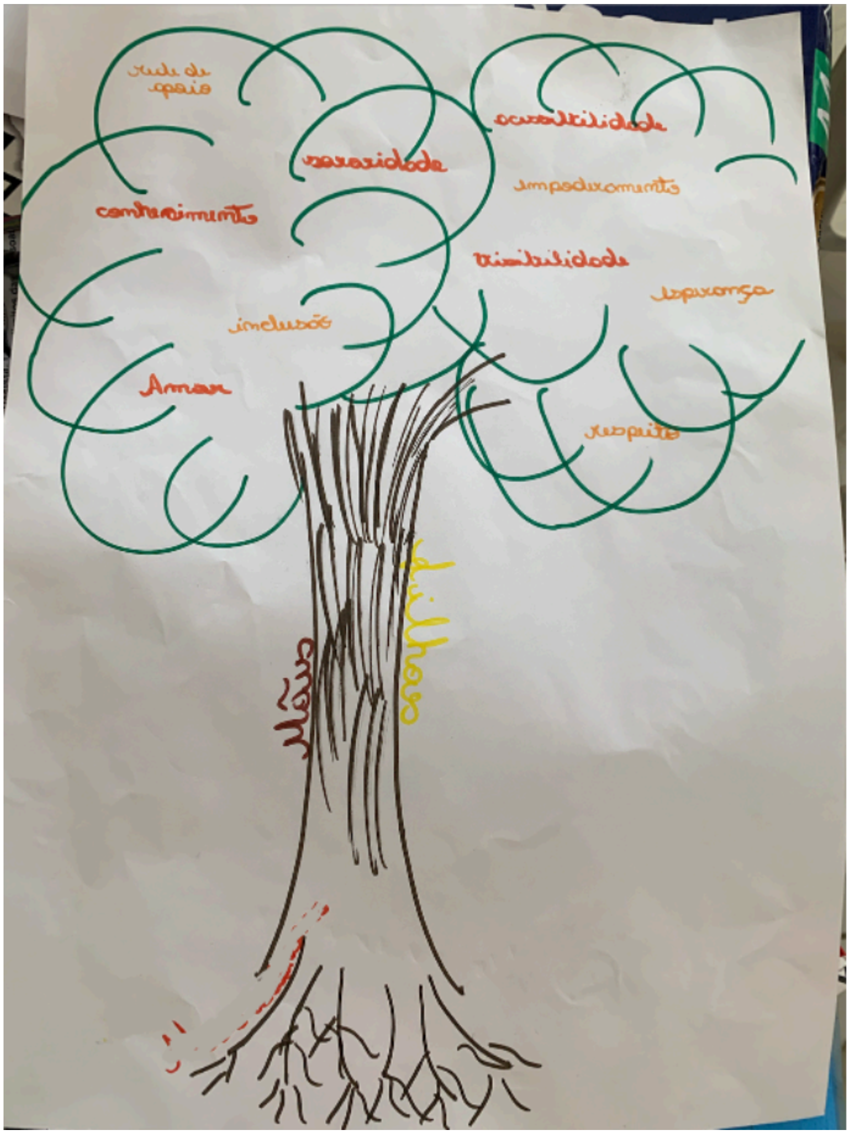

Image: *drawing of a tree representing a mothers’ network during the workshops in Bahia. The words in the tree read: support network, knowledge, love, inclusion, visibility, respect, hope, solidarity, empowerment and accessibility. The word on the left hand side of the tree reads ‘mothers’ and on the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

Instrumental Support

Mothers listed key functions of mothers’ networks as providing mutual aid, or facilitating and providing services, such as physiotherapy, psychosocial support or extra-curricular education programmes. We can therefore consider this to be a form of instrumental support, or practical assistance to meet needs, such as financial assistance, providing services, or another form of help that can help reduce stress during times of adversity[61].

Some mothers' networks more explicitly aim to provide instrumental support, which was seen as firmly linked to the health and wellbeing of mothers and children, especially when families were faced with complex health and care 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 the mother who established the network saw as ***'essential to be able to educate, deal with the child, with microcephaly... congenital Zika virus syndrome'.***

Instrumental support could also consist of mutual aid, a horizontal support structure between members that could consist of pooling financial or practical resources to facilitate activities or help members in need. For example, a member of a network in Rio de Janeiro described how they pooled finances to be able to rent a space that was used to collect and distribute donations via 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 donations.'***

Informational support

Informational support, often referred to as knowledge exchange by mothers, was a main function of networks and facilitated practical knowledge-sharing from mother to mother. Informational support also provided informal orientation and guidance to the labyrinthic health, social care and education systems, including about the rights that children have access to by law and the systems and services that are supposed to uphold those rights. Since mothers often become mothers of children with disabilities 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.

Knowledge exchange was critical for empowerment, as mothers learned from each other's experiences and gained confidence in advocating for themselves and their children, individually, but in some cases were also empowered to act collectively. For some mothers, networks are the only place where they learn about the rights of their children and how to access these rights.

> ***'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].'***
> - Mother, Autism network, Bahia

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[61] Cohen & Wills, 1985. Stress, social support, and the buffering hypothesis. Psychological Bulletin. 98(2). Pp. 310-357.

Activism for Systems Change & Mediation

Some mothers' networks also facilitated activism that focussed on system change, usually locally but in some cases taking part in national campaigns for policy reform. Sometimes, activism could take place in the form of ad-hoc, targeted campaigns, such as protests for accessible public transport. Other networks were involved in longer-term civic engagement with local councils, disability councils or research and policy discussion spaces, such as the national disability and health conferences.

Another function of networks at the systemic level was acting as an intermediary between families and services in order to get access to goods and services that would otherwise be inaccessible to families. As was the case for a network for families of children with CZS in Bahia, the mother who set up the network described how ***'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, orthopaedics, those things.'*** The network therefore functioned as an intermediary between families and services to negotiate for discounted rates that enabled families access to basic services, who would have otherwise faced financial or bureaucratic barriers.

6. Conclusion and Recommendations

In conclusion, people with disabilities and their families in Brazil, particularly in peripheral areas, face significant challenges due to deep-rooted inequalities and systemic barriers. These include limited access to healthcare, social assistance, and education, as well as the ongoing burden of care often placed on women, especially Black and poor women. The lack of support, slow diagnoses, persisting biomedical approach to disability and inadequate care systems contribute to the struggles of these families, with access to services heavily influenced by race, income, and location. However, community networks have been established by mothers, offering vital support and advocating for change.

Addressing the issues outlined in this report requires a stronger, more inclusive systems with better access to resources, information, and support, along with targeted policy reforms. The authors offer some recommendations for policy and further research below.

1. Develop public policies to guarantee the right of all people with disabilities to live with their families or communities and end institutionalization. Provide sufficient support so that all people with disabilities and their families can live a dignified life, regardless of their socioeconomic status.
2. Reinvest in the SUS, expand health services outside of urban centres and improve transport links between Black, indigenous and quilombo communities.

3. Guarantee timely access to diagnosis and healthcare, including post-diagnostic support for people with disabilities and their families in peripheral areas, reducing waiting times and simplifying access.
4. Revise the eligibility criteria for the BPC disability benefit to decouple it from family income and make it accessible to more people with disabilities, especially those in peripheral areas.
5. Implement a means-tested support program to absorb the higher costs of having a disability, including remuneration for care.
6. Implement targeted awareness campaigns on women's rights, the rights of people with disabilities, and welfare programs and services in peripheral communities, and provide comprehensive support to guide families in accessing welfare programs and services for women and people with disabilities.
7. Develop and promote public policies for the inclusion of students with disabilities in all spheres and modalities of education from an intersectional perspective, with special attention to black and indigenous people with disabilities, seeking not only access, but also retention and success of this group, promoting compliance with legislation regarding the promotion of special education from the perspective of inclusive education.
8. Improve inclusive education practices in schools that serve Black, indigenous and peripheral communities, investing in teacher training, resources, classroom support, and school outreach.
9. Remove barriers that prevent people with disabilities and mothers of children with disabilities from entering the formal labor market, implementing public policies that address structural ableism and racism in education, training, and employment.
10. Provide adequate housing for people with disabilities, especially Black, indigenous and peripheral people with disabilities and their families.
11. Ensure that the National Care Policy is finalized and implemented as soon as possible, noting specific issues for Black and indigenous people with disabilities and their families and defining the specifics of how the policy will ensure universal care for this population.
12. Provide support for organizations of people with disabilities to deliver training for caregivers of people with disabilities.
13. Support further research into negligent, irresponsible and abusive behaviour towards mothers and children from fathers related to disability diagnosis. Develop policies that hold perpetrators responsible and protect the rights of mothers and children with disabilities.