

SUBMISSION TO THE COMMITTEE ON THE ELIMINATION OF DISCRIMINATION  
AGAINST WOMEN (CEDAW)

ALTERNATIVE REPORT UNDER THE LIST OF ISSUES OF

# BRAZIL

*Women and girls with disabilities and women caregivers  
from Black and indigenous communities*

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### I. About the authors

**Minority Rights Group (MRG)** is an international NGO working to secure the rights of ethnic, religious and linguistic minorities and indigenous peoples worldwide. MRG has consultative status with the United Nations Economic and Social Council (ECOSOC), observer status with the African Commission on Human and Peoples' Rights (ACHPR) and is a civil society organization registered with the Organization of American States (OAS).

**Vidas Negras com Deficiência Importam (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. We mobilise through civil society actions and advocacy.

**Rede Valentes** is a CSO that acts as a network of reception, support and feminist training for women, especially those in situations of social vulnerability, with counselling, leadership training and awareness initiatives.

**Instituto Kevyn Johnson - Projeto Marias** are a collective of women who are mothers of children with disabilities from the Manguinhos community in Rio de Janeiro.

**Coletivo Acessibilindígena** was created by indigenous people with disabilities belonging to various peoples to address the issue of accessibility and indigenous struggle!

### II. Methodology

The data presented in this report was collected and analyzed by the co-submitting organizations, including organizations of Black and indigenous women with disabilities. We also used data from academic research. Data includes case studies, surveys, relevant academic research, statistics and observations from these organizations. This report was prepared following the principle of 'Nothing About Us, Without Us', in consultation and partnership with representatives of Black and indigenous women with disabilities and women caregivers.

Women and girls with disabilities and women caregivers belonging to Black and indigenous communities face multiple, intersecting and aggravated forms of discrimination based on disability, race/ethnicity/colour, language, gender, culture and other identity factors that cannot be separated and therefore need to be highlighted and addressed by relevant bodies and organizations at local, national and international levels. In this report, 'Black' is used to refer to those who declare themselves black (*pretos*) and mixed race (*pardos*) according to the categories used by the Brazilian Census carried out by the Brazilian Institute for Geography and Statistics (IBGE) and include *quilombola*<sup>1</sup> communities in Brazil.

### III. Introduction

Brazil is a signatory to the UN Convention on the Elimination of Discrimination against Women (CEDAW), having ratified it in 1984. It accepted individual complaints through the Optional Protocol in 2002. This

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<sup>1</sup> Quilombolas are a social category resulting from the historical process of resistance against enslavement in Brazil. Traditionally defined along ethnic-racial lines in relation to the descendants of enslaved Africans or Afro-Brazilians who escaped and resisted slavery, quilombola communities have also been associated with forms of political and social organization developing in parallel with, and as an alternative to, the slavocrat and racist society. See Ilka Boaventura Leite. 2015. The Brazilian quilombo: 'race', community and land in space and time, *The Journal of Peasant Studies*, 42:6, 1225-1240, DOI: 10.1080/03066150.2015.1016919

submission will refer to relevant articles of the treaty while focussing on women and girls with disabilities and women caregivers belonging to Black and indigenous communities. Of the total population, 45 million people are classified as having some type of disability, that is, a quarter of the Brazilian population or approximately 24%. From this segment, the 2010 Census shows that 24.3% of people with disabilities are black, and 56% identify as female.<sup>2</sup>

The following themes will be discussed:

- Lack of disaggregated data and public policies
- Violence
- Access to healthcare and care
- Gendered familial responsibilities and absence of support from the state
- Access to education
- Access to work
- Disaster risk reduction

#### IV. Relevant State Policies

1. In addition to CEDAW, Brazil is a signatory to the UN Convention on the Rights of Persons with Disabilities (CRPD), having ratified it with a constitutional amendment, and its Optional Protocol, which makes explicit mention of persons with disabilities who are subject to multiple or aggravated forms of discrimination based on race, color, sex, language, religion, political or other opinion, nationality, ethnicity, indigenous or social origin, property, birth, age or other status, in its Preamble. Article 6 also specifically mentions women and girls with disabilities who are subject to multiple discrimination.<sup>3</sup>
2. Brazil also has several state policies and national strategies designed to uphold the rights of people with disabilities. For example, the Brazilian Law for the Inclusion of Persons with Disabilities (Statute of Persons with Disabilities)<sup>4</sup>; The National Policy for the Integration of the Person with Disability,<sup>5</sup> relating to insertion of people with disabilities into the labour market; the National Policy on Special Education from the Perspective of Inclusive Education (PNEEPEI)<sup>6</sup>; and Law No. 10.216/01 concerning the protection and rights of 'persons with mental disorders'.<sup>7</sup> The 2012 National Quota Law<sup>8</sup> allocates 50% of places for black and indigenous students and students with disabilities to enter into federal universities.
3. Brazil does not have a policy specifically aimed at addressing the healthcare needs of the quilombola population, a right already guaranteed to indigenous peoples via the National Health Care Policy for Indigenous Peoples (2002)<sup>9</sup>. The quilombolas are included under the remit of the National Integral

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<sup>2</sup> 2010 Census. Available at: <https://censo2010.ibge.gov.br/>

<sup>3</sup> Convention on the Rights of Persons with Disabilities, Preamble, para. p. 2006.

<sup>4</sup> Brazil. 2015. LEI N° 13.146, DE 6 DE JULHO DE 2015.

<sup>5</sup> Brazil. 1999. DECRETO N° 3.298, DE 20 DE DEZEMBRO DE 1999.

<sup>6</sup> Brazil. 2008. POLÍTICA NACIONAL DE EDUCAÇÃO ESPECIAL NA PERSPECTIVA DA EDUCAÇÃO INCLUSIVA.

<sup>7</sup> Brazil. 2001. LEI No 10.216, DE 6 DE ABRIL DE 2001.

<sup>8</sup> Brazil. 2012. LEI N° 12.711, DE 29 DE AGOSTO DE 2012. Available at: [http://www.planalto.gov.br/ccivil\\_03/\\_ato2011-2014/2012/lei/l12711.htm](http://www.planalto.gov.br/ccivil_03/_ato2011-2014/2012/lei/l12711.htm)

<sup>9</sup> Fundação Nacional de Saúde. Política Nacional de Atenção à Saúde dos Povos Indígenas. - 2ª edição - Brasília: Ministério da Saúde. Fundação Nacional de Saúde. 2002. Available at: [https://bvsms.saude.gov.br/bvs/publicacoes/politica\\_saude\\_indigena.pdf](https://bvsms.saude.gov.br/bvs/publicacoes/politica_saude_indigena.pdf)

Health Policy for the Black Population,<sup>10</sup> which still lacks effective implementation and budgetary allocation. The division of responsibilities between the federal, (subnational) state and municipal spheres, and the inadequate coordination between these three levels, also compromises the effectiveness of public health policies. Resources are used without considering the specificities, vulnerabilities and prominent diseases among the quilombola population<sup>11</sup>. These gaps also affect women with disabilities and women caregivers belonging to quilombola communities.

4. Law No. 13.836 of 4 June 2019 adds provisions to Art. 12 of the Maria Penha Law No. 11.340 of 7 August 2006 to protect women who are victims of domestic and family violence and makes documentation on the status of disabled women victims of domestic or family aggression mandatory. However, most instances of violence against women with disabilities are not reported because they are perpetrated by family members or intimate partners whom women often rely on for care or economic support and because reporting mechanisms are not accessible<sup>12</sup>.
5. There is an absence of a focused national care policy that promotes the autonomy of people with disabilities to choose and pay for their own care. There is also a lack of a policy that recognizes the work of caregivers and allows for their adequate remuneration, including family caregivers or professional caregivers, who are mostly Black women. Lack of a care policy disproportionately impacts Black and other marginalised people with disabilities and women family members who do not have the financial means to pay for professional care and who suffer socioeconomically due to loss of paid employment. Whilst the proposed National Care Policy (PL 2797/2022) is being considered by the Federal Senate provides robust legislation addressing issues of carers and people dependent on care, it is yet to be approved or implemented<sup>13</sup>.

## **V. Lack of Disaggregated Data and Public Policies - Article 2 of CEDAW**

6. Lack of disaggregated data on gender, race and disability makes it difficult for the Brazilian state to ensure legal protection of Black and indigenous women and girls with disabilities and caregivers through the development of specific public policies to eliminate discrimination in line with Article 2. This population is therefore underserved or missed by general policies directed at children, people with disabilities, women or Black and indigenous populations.
7. The lack of published disaggregated data that includes race, disability and age makes obtaining official numbers of women and girls with disabilities belonging to Black and indigenous communities difficult. Whilst data on disability and race is certainly collected within the health and social service sectors, it is not made public and is difficult to retrieve. Disaggregated disability data showing the race/colour self-identity category was only published for the first time in 2023 and failed to include the category 'indigenous' in official publications<sup>14</sup>.

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<sup>10</sup> Brazil. 2017. Ministério da Saúde. Política Nacional de Saúde Integral da População Negra: uma política para o SUS. 3ª ed. Brasília: Editora do Ministério da Saúde, 44p. Available at:

[https://bvsms.saude.gov.br/bvs/publicacoes/politica\\_nacional\\_saude\\_populacao\\_negra\\_3d.pdf](https://bvsms.saude.gov.br/bvs/publicacoes/politica_nacional_saude_populacao_negra_3d.pdf)

<sup>11</sup> Anunciação, D., Pereira, L. L., Silva, H. P., Nunes, A. P. N., & Soares, J. O. (2022). (Des) caminhos na garantia da saúde da população negra e no enfrentamento ao racismo no Brasil. *Ciência & Saúde Coletiva*, 27, 3861-3870.

<sup>12</sup> Agência Câmara de Notícias. 2022. Debatedores alertam para aumento da violência doméstica contra mulheres com deficiência. Available at: <https://www.camara.leg.br/noticias/925666-debatedores-alertam-para-aumento-da-violencia-domestica-contra-mulheres-com-deficiencia/>

<sup>13</sup> Senado Federal. 2022. Projeto de Lei nº 2797, de 2022. Available at: <https://www25.senado.leg.br/web/atividade/materias/-/materia/155126>

<sup>14</sup> IBGE. 2023. Pesquisa Nacional por Amostra de Domicílios Contínua: Pessoas com deficiência 2022.

8. Data about indigenous women and girls with disabilities is particularly scarce and underreported which makes it even more difficult for them to access basic services and creates barriers to the development of policies and programmes to reach this population<sup>15</sup>.
9. There is no official data collection on the numbers or situations of caregivers of people with disabilities, but it is estimated that the vast majority are unpaid women family members or low-paid Black women domestic workers. Black women are twice as likely to be engaged in domestic work at 67.3% in comparison to non-Black women at 32.7%, a racial disparity that has grown in the last decade<sup>16</sup>. Likewise, women with disabilities are overrepresented in domestic work at 18.8% in comparison to 12.2% of women without disabilities<sup>17</sup>. It is therefore surmised that most of the care work for people with disabilities, both paid and unpaid, is undertaken by Black women in Brazil, with a disproportionate number of them also having a disability themselves.

## VI. Violence – Articles 2, 3 & 5

10. Black people with disabilities are particularly vulnerable to experiencing violence on account of their intersecting identities, with Black women with disabilities the most likely group to experience violence. Whilst no official disaggregated data exists, insights can be drawn from the Map of Violence<sup>18</sup>, which is based on the Information System on Mortality (SIM) and the Information System on Notifiable Diseases (Sinan) of the Ministry of Health and indicates that women and girls, the Black population and the population with disabilities are at heightened risk of experiencing violence.
11. Data indicated that in 2019, Black women accounted for 66.0% of the total number of women murdered in Brazil, with a mortality rate of 4.1 per 100,000 inhabitants, compared to a rate of 2.5 for non-Black women<sup>19</sup>.
12. Analysis of reports of violence against people with disabilities from the same 2019 dataset shows very high rates of violence against people with intellectual disabilities (36.2 reports per 10,000 people with intellectual disabilities), in comparison to people with other types of disabilities (11.4 reports per 10,000 people with physical disabilities; 3.6 per 10,000 for people with hearing impairments; and 1.4 reports per 10,000 for people with visual disabilities). The rates are particularly high for women with intellectual disabilities, which is attributed to the higher rates of sexual violence experienced by this sub-group. In general, reporting data indicates that rates of violence against women are more than twice as high as those of men, except when the victim is visually impaired<sup>20</sup>.
13. Research reveals that mothers of children with disabilities experience physical and psychological domestic violence from the fathers of their children. Sometimes, mothers reported abuse on account of their child's disability or diagnosis, which was 'blamed' on the mother<sup>21</sup>.
14. Victims of domestic violence are not always able to access appropriate support and leave domestic violence situations because of financial reliance on male partners and lack of support from the state.

<sup>15</sup> Information from Acessibilindígena. 2024.

<sup>16</sup> IBGE. 2022. Pesquisa Nacional por Amostra de Domicílios Contínua (Pnad Contínua). Available at: <https://www.dieese.org.br/infografico/2023/trabalhoDomestico2023.html>

<sup>17</sup> IBGE. 2023. Pesquisa Nacional por Amostra de Domicílios Contínua.: Pessoas com deficiência 2022.

<sup>18</sup> <sup>III</sup> *Atlas da Violência 2021*. Available at: <https://www.ipea.gov.br/atlasviolencia/arquivos/artigos/1375-atlasdaviolencia2021completo.pdf>.

<sup>19</sup> Ibid.

<sup>20</sup> *Atlas da Violência 2021*. Available at: <https://www.ipea.gov.br/atlasviolencia/arquivos/artigos/1375-atlasdaviolencia2021completo.pdf>

<sup>21</sup> Avery & VNDI. 2023. Projeto das Mães (unpublished study).

Mothers of children with disabilities are often unable to work owing to intense care routines involving administration, taking children to medical or therapy appointments, and physical care work. This and the resulting social isolation make it difficult for them to leave abusive situations as they have no other means or time to establish the economic or social conditions to leave the abusive relationship<sup>22</sup>.

15. Courts tend to favour fathers over mothers, which makes it difficult for women to get the fathers of their children to pay child welfare support, or the Pensão Alimentícia, which is a right according to Articles 1.694 and 1.710 of the 2002 Civil Code<sup>23</sup>. Partners report that the situation can be exacerbated for Black mothers of children with disabilities who are more likely to experience poverty and less likely to be able to access state support or justice through the courts on account of racial discrimination<sup>24</sup>.

### Case Study: SMJ

16. Black women with disabilities are more likely to fall victim to violation of their right to freedom and justice in relation to modern-day slavery. This is illustrated in the example of the case of SMJ (anonymised in accordance with CEDAW requirements), a 49-year-old Black deaf woman who was found in Santa Catarina in June 2023 in slavery-like conditions. Since the age of nine years old, SMJ had been working in the home of a judge, without access to her basic rights including learning sign language. She was not registered on the Cadastro de Pessoas Físicas (Natural Persons Register) until 2019 and was without social security coverage or health insurance and was illiterate. Her family reported that she had been taken from her mother, who was trying to escape domestic violence. Her mother spent the rest of her life looking for her, eventually dying in 2016<sup>25</sup>. Despite evidence of serious violations of her human rights, SMJ was returned to the place where she had been enslaved. The Brazilian judicial system did not deliver justice, in part because it did not recognize that SMJ did not have the linguistic tools to communicate her will<sup>26</sup>.

## VII. Access to Healthcare and Care - Article 12

17. There is a dire lack of access to appropriate healthcare and care services for Black and indigenous communities, including disability diagnosis, maternal health care, preventative health care, care support and family planning services. Lack of access is compounded for women members of these communities with disabilities and women family caregivers owing to multiple and intersecting discrimination on grounds of race, disability and gender. Lack of access to healthcare and care services leads to the debilitation of both people with disabilities and their caregivers, which includes worsening pre-existing health conditions and the creation of further impairments.

<sup>22</sup> Sanches and Pan. 2018. Instituto João Clementes Blog. Violência doméstica: reflexão sobre a alta vulnerabilidade de mães de crianças com deficiência intelectual. Available at: <https://ijc.blog.br/2018/03/02/violencia-domestica-reflexao-sobre-a-alta-vulnerabilidade-de-maes-de-criancas-com-deficiencia-intelectual/>

<sup>23</sup> Brazil. 2002. Law N° 10,406 of 10 January 2002. Available at: [http://legislacao.planalto.gov.br/legisla/legislacao.nsf/Viw\\_Identificacao/lei%2010.406-2002?OpenDocument](http://legislacao.planalto.gov.br/legisla/legislacao.nsf/Viw_Identificacao/lei%2010.406-2002?OpenDocument)

<sup>24</sup> Information from VNDI. 2024.

<sup>25</sup> Vassallo, L. 2023. Mãe de mulher escravizada por desembargador morreu procurando filha . Metrôpoles. Available at: <https://www.metrolopes.com/sao-paulo/mae-de-mulher-escravizada-por-desembargador-morreu-procurando-filha>

<sup>26</sup> Guimarães, P. 2023. DE VOLTA À CASA GRANDE. THE INTERCEPT BRAZIL. Available at: <https://www.intercept.com.br/2023/12/11/desembargador-denunciado-por-trabalho-escravo-usou-manipulacao-psicologica-para-vitima-voltar-a-sua-casa-revelam-laudos/>

18. Black people experience a general lack of access to healthcare in Brazil<sup>27</sup>, which is compounded for Black women because of institutional racism and sexism.<sup>28</sup> In an assessment of access to preventative health services, Black women account for 7.9% of those with ‘good’ access, as compared to their white counterparts who account for 15.4%.<sup>29</sup>
19. There is also lack of general access to healthcare for people with disabilities<sup>30</sup>, and especially women with disabilities<sup>31</sup>, caused by institutional ableism. Research indicates that Black and quilombola communities experience a general lack of access to healthcare owing to lower socioeconomic and education levels, institutional racism, sexism, violence, failure to respect culture and ethnic diversity and poorer access to private healthcare<sup>32,33</sup>.
20. The Health Care Law (Law 8080/90) supporting the Unified Health System (Sistema Único de Saúde or SUS) has been successful in improving health equity for Brazilians but system reform since 2016 has led to defunding of the service, widening of geographical inequalities and worsening of health indicators, particularly amongst indigenous communities<sup>34</sup>.
21. Black people are more likely to be solely dependent on SUS; 67% of users are Black and 47.2% white, in comparison to 55.5% and 43.5% of Brazil’s population, respectively<sup>35</sup>. Dependence on the SUS is linked to the low levels of income of the Black population<sup>36</sup>, which makes them less likely to be able to access private healthcare insurance. Healthcare insurance offers easier access to some services, facilities, professionals and technologies<sup>37</sup> and is correlated with greater utilization of healthcare services overall<sup>38</sup>. This has a disproportionate impact on Black women and children with disabilities and their ability to access appropriate healthcare to meet their needs.

<sup>27</sup> 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. Available at: <https://doi.org/10.1590/0034-7167-2018-0834>

<sup>28</sup> Goes, Emanuelle Freitas e Nascimento, Enilda Rosendo do. 2013. Mulheres negras e brancas e os níveis de acesso aos serviços preventivos de saúde: uma análise sobre as desigualdades. *SciELO. Saúde em Debate*. 2013, v. 37, n. 99, pp. 571-579. Available at: <https://www.scielo.br/j/sdeb/a/kw9SwjT5SHMYty6dhTYvsGg/?lang=pt> Epub 13 Feb 2014. ISSN 2358-2898.

<sup>29</sup> Goes, Emanuelle Freitas e Nascimento, Enilda Rosendo do. 2013. Mulheres negras e brancas e os níveis de acesso aos serviços preventivos de saúde: uma análise sobre as desigualdades. *SciELO. Saúde em Debate*. 2013, v. 37, n. 99, pp. 571-579. Available at: <https://www.scielo.br/j/sdeb/a/kw9SwjT5SHMYty6dhTYvsGg/?lang=pt> Epub 13 Feb 2014. ISSN 2358-2898.

<sup>30</sup> da Cunha MAO, Santos HF, de Carvalho MEL, Miranda GMD, de Albuquerque MDSV, de Oliveira RS, de Albuquerque AFC, Penn-Kekana L, Kuper H, Lyra TM. Health Care for People with Disabilities in the Unified Health System in Brazil: A Scoping Review. *Int J Environ Res Public Health*. 2022 Jan 28;19(3):1472. doi: 10.3390/ijerph19031472. PMID: 35162497; PMCID: PMC8834994.

<sup>31</sup> Nicolau, Stella Maris, Schraiber, Lilia Blima e Ayres, José Ricardo de Carvalho Mesquita. Mulheres com deficiência e sua dupla vulnerabilidade: contribuições para a construção da integralidade em saúde. *Ciência & Saúde Coletiva* [online]. 2013, v. 18, n. 3, pp. 863-872. Available at: <https://doi.org/10.1590/S1413-81232013000300032> Epub 28 Mar 2013. ISSN 1678-4561. <https://doi.org/10.1590/S1413-81232013000300032>.

<sup>32</sup> 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. Available at: <https://doi.org/10.1590/0034-7167-2018-0834>

<sup>33</sup> Goes, Emanuelle Freitas e Nascimento, Enilda Rosendo do. 2013. Mulheres negras e brancas e os níveis de acesso aos serviços preventivos de saúde: uma análise sobre as desigualdades. *SciELO. Saúde em Debate*. 2013, v. 37, n. 99, pp. 571-579. Available at: <https://www.scielo.br/j/sdeb/a/kw9SwjT5SHMYty6dhTYvsGg/?lang=pt#> Epub 13 Feb 2014. ISSN 2358-2898.

<sup>34</sup> Ortega & Pele. 2023. Brazil’s unified health system: 35 years and future challenges. *The Lancet Regional Health – Americas*. 28:100631. Available at: [https://www.thelancet.com/journals/lanam/article/PIIS2667-193X\(23\)00205-3/fulltext](https://www.thelancet.com/journals/lanam/article/PIIS2667-193X(23)00205-3/fulltext)

<sup>35</sup> Brasil. 2017. Ministério da Saúde. Secretaria de Gestão Estratégica e Participativa. Departamento de Apoio à Gestão Participativa e ao Controle Social. Política Nacional de Saúde Integral da População Negra : uma política para o SUS / Ministério da Saúde, Secretaria de Gestão Estratégica e Participativa, Departamento de Apoio à Gestão Participativa e ao Controle Social. – 3. ed. – Brasília : Editora do Ministério da Saúde, 2017. 44 p. ISBN 978-85-334-2515-6

<sup>36</sup> Ibid.

<sup>37</sup> 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.

<sup>38</sup> 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.

22. Whilst there is a lack of gender-specific research, Black and indigenous children experience higher infant mortality rates and higher risk of preventable death such as linked to malnutrition, diarrhoea, influenza and pneumonia<sup>39</sup> and indigenous disability activists report that the absence of trained healthcare professionals prevents indigenous women and children with disabilities from obtaining adequate care<sup>40</sup>.
23. The regions that experience the greatest inequality in healthcare access are the north and the northeast, which are also the poorest regions and have the largest Black populations<sup>41</sup>. The poorest children in this region access healthcare services the least, in comparison to other regions and age groups<sup>42</sup>.
24. Black populations also have poorer access to high complexity (specialized) health services<sup>43</sup>, due to the concentration of these services to urban centres, which are dominated by the white population<sup>44</sup>. This disparity in access has a specific impact on Black and indigenous children with disabilities who rely on high complexity health services, which include specialist therapies and surgeries.
25. Black women with disabilities and caregivers of children with disabilities complain of discrimination by doctors that prevents or delays access to diagnoses and official disability registration, which in turn conditions access to welfare programmes<sup>45</sup> Black mothers of autistic children in Bahia reported that they were denied a medical diagnosis because their children did not 'look autistic', an excuse that Black autistic activists put down to racism<sup>46</sup>.
26. In addition, Black caregivers of children with disabilities report experiencing multiple barriers to accessing healthcare via the SUS owing to high levels of bureaucracy, a lack of information and support in navigating the system and racial discrimination which results in uneven and unpredictable access to health services<sup>47</sup>.

## Case Study on Zika

27. The 2015 Zika epidemic overwhelmingly impacted Black women, with the highest prevalence in Brazil's northeastern states<sup>48</sup>, which have a majority Black population. The epidemic caused an estimated 14,558 babies to be born with Congenital Zika Syndrome (CZS) to infected pregnant women between 2015 and 2017, although only 2,952 received a confirmed diagnosis from the Brazilian Ministry of Health<sup>49</sup>. Zika is an arbovirus transmitted via mosquitos and sexual intercourse.

<sup>39</sup> Rebouças et al. 2022. Ethnoracial inequalities and child mortality in Brazil: a nationwide longitudinal study of 19 million newborn babies. *The Lancet Global Health*. 10(10), E1453-E1462. Available at: [https://www.thelancet.com/journals/langlo/article/PIIS2214-109X\(22\)00333-3/fulltext](https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(22)00333-3/fulltext)

<sup>40</sup> Information from Acessibilindígena. 2024.

<sup>41</sup> 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.

<sup>42</sup> Ibid.

<sup>43</sup> High complexity health services are generally of higher cost and rely on specialist professionals and technologies. Examples of services include intensive therapies, cancer treatments and specialist surgeries.

<sup>44</sup> Instituto de Pesquisa Econômica Aplicada (Ipea). 2021. DESIGUALDADES RACIAIS E DE RENDA NO ACESSO À SAÚDE NAS CIDADES BRASILEIRAS. Available at: [https://repositorio.ipea.gov.br/bitstream/11058/11454/1/td\\_desigualdades\\_raciais\\_renda\\_publicacao\\_preliminar.pdf](https://repositorio.ipea.gov.br/bitstream/11058/11454/1/td_desigualdades_raciais_renda_publicacao_preliminar.pdf)

<sup>45</sup> VNDI. 2022. Experience reports collected from VNDI members in 2022.

<sup>46</sup> Avery & VNDI. 2023. Projeto das Mães (unpublished study).

<sup>47</sup> Ibid.

<sup>48</sup> Vissoci, J. R. N., Rocha, T. A. H., da Silva, N. C., de Sousa Queiroz, R. C., Fonseca Thomaz, E. B. A., Vasconcelos Maia Amaral, P., ... Staton, C. (2018). Zika virus infection and microcephaly: Evidence regarding geospatial associations. *PLoS Neglected Tropical Diseases*, 12(4), 1–166. <https://doi.org/10.1371/journal.pntd.0006392>

<sup>49</sup> Pan American Health Organization / World Health Organization. 2018. Zika suspected and confirmed cases reported by countries and territories in the Americas Cumulative cases, 2015-2017. Updated as of 04 January 2018. Available at:

The spread of Zika and higher incidence of CZS has been linked to poorer sanitation, malnutrition, poor access to contraception and poor living conditions<sup>50</sup>, which are more prevalent amongst Black communities across the country<sup>51</sup>.

28. Pregnant women infected with Zika are at high risk of the foetus developing CZS; a neurological condition that in most cases leads to lifelong physical and intellectual and multiple disabilities. Although the health emergency was declared over in 2016, there is still no vaccination against Zika and cases continue throughout the country. According to the Ministry of Health, 84.3% of the mothers of children with CZS are black, around two-thirds of whom are located in the northeast of Brazil<sup>52</sup>. The vast majority were also young (71.4% between 15 and 29 years old); and single, separated or widowed (49.4%).<sup>53</sup>
29. Due to neglect by the authorities and lack of public policies relating to care, access to therapeutic and health services, financial support, access to education and accessible housing, families of children with CZS have been disproportionately impacted by structural discrimination that prevents them from securing their social, economic and cultural rights.<sup>54</sup>
30. Families have a lack of information on psychological and social services for children with Zika-related disabilities<sup>55</sup>, as well as an inability to return to work, many hours traveling to doctor's appointments, struggles to access basic medicine/ medical equipment.<sup>56</sup> Many mothers were forced to give up paid work or education to care for their children full-time. They suffer from mental and physical health problems because of the lack of support, inadequate access to healthcare. Many experience financial difficulties and live off the charity of family and community members owing to the inadequacy of state welfare benefits to cover the additional costs of raising a child with complex health needs<sup>57</sup>.
31. Children with CZS have had to wait months or years for lifesaving or life-improving spinal surgeries or other interventions<sup>58</sup>. Often families are forced to turn to community fundraising to cover costs of private treatment rather than waiting on SUS services. Research shows that barriers to access to specialised health services for children with CZS include fragmentation, inadequacy and culturally and geographically inaccessibility of services linked to underfunding of the SUS<sup>59</sup>.
32. Since 2016, families have been organising through Zika associations, mainly led by black mothers, to negotiate access to public policies that secure the quality of life of themselves and their children. Whilst the families have been successful in guaranteeing access for some children with CZS to a

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[https://www.paho.org/hq/index.php?option=com\\_docman&view=download&category\\_slug=cumulative-cases-pdf-8865&alias=43296-zika-cumulative-cases-4-january-2018-296&Itemid=270&lang=en](https://www.paho.org/hq/index.php?option=com_docman&view=download&category_slug=cumulative-cases-pdf-8865&alias=43296-zika-cumulative-cases-4-january-2018-296&Itemid=270&lang=en)

<sup>50</sup> Barbeito-Andrés, J., Pezzuto, P., Higa, L. M., Dias, A. A., Vasconcelos, J. M., Santos, T. M. P., ... Garcez, P. P. (2020). Congenital Zika syndrome is associated with maternal protein malnutrition. *Science Advances*, 6(2), 1–12. <https://doi.org/10.1126/sciadv.aaw6284>

<sup>51</sup> Boing, A. F., Boing, A. C., & Subramanian, S. V. (2021). Inequalities in the access to healthy urban structure and housing: an analysis of the Brazilian census data. *Cadernos de Saúde Pública*, 37(6). <https://doi.org/10.1590/0102-311X00233119>. Available at: <https://www.scielo.br/j/csp/a/D9SFbBDMsTyf7F5dMfkTjJm/?lang=en>

<sup>52</sup> Center for Reproductive Rights. 2018. *Unheard Voices: Women's Experiences with Zika, Brazil*. New York.

<sup>53</sup> Brasil. 2017. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Vigilância de Doenças e Agravos Não Transmissíveis e Promoção da Saúde. Saúde Brasil 2015/2016: uma análise da situação de saúde e da epidemia pelo vírus Zika e por outras doenças transmitidas pelo *Aedes aegypti*. Available at: [http://bvsms.saude.gov.br/bvs/publicacoes/saude\\_brasil\\_2015\\_2016.pdf](http://bvsms.saude.gov.br/bvs/publicacoes/saude_brasil_2015_2016.pdf)

<sup>54</sup> Center for Reproductive Rights. 2018. *Unheard Voices: Women's Experiences with Zika, Brazil*. New York.

<sup>55</sup> Ibid.

<sup>56</sup> Ibid.

<sup>57</sup> Avery & VNDI. 2023. Projeto das Mães (unpublished study).

<sup>58</sup> Information from Mães de Anjos. 2024.

<sup>59</sup> Albuquerque, M. 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.

lifelong pension and improved access to the BPC, therapies, and accessible housing, this progress is incremental and state support for these families remains extremely inadequate.

#### **VIII. Gendered familial responsibilities and absence of support from the state - Articles 5, 13 & 16**

33. Caregivers of children with disabilities are overwhelmingly mothers, owing to high rates of paternal abandonment and the gendered economy of care. According to a study by Instituto Baresi in 2012, around 78% of children with disabilities were abandoned by their fathers before the age of five<sup>60</sup>. Whilst there is no official data disaggregated by race or ethnicity, some mothers of children with disabilities interviewed in a 2023 study estimated that paternal abandonment rates within Black families is as high as 90%<sup>61</sup>.
34. Familial care policies, such as conditions to accessing the BPC being based on family income and a lack of a national care policy that provides remuneration for care, give children with disabilities and their families little choice about who provides care. This places the burden of unpaid care largely on women and girls, usually mothers but also sisters, grandmothers, aunts and other family members. Black families are less likely to be able to outsource care than white families because of socioeconomic limitations and are more likely to have to stop work to take care of their child.
35. Black women in Brazil are already more likely to face barriers to accessing preventative healthcare owing to institutional racism.<sup>62</sup> There is also evidence that Black women caregivers are likely to develop disabilities or health comorbidities owing to the burden of caregiving without adequate support<sup>63</sup>.
36. Women caregivers of Black children with disabilities are often unaware of the rights of themselves and their children to access welfare programmes, benefits and services. Interviews with healthcare professionals, service centre managers and mothers of children with disabilities revealed that this information is often not shared with families in healthcare settings, and so families remain unaware of their rights<sup>65</sup>. A lack of assistance in navigating bureaucratic systems was a particular barrier within poor Black and favela communities<sup>66</sup>.
37. Women caregivers of Black children with disabilities also reported denial of access to other welfare programmes, such as Bolsa Família, a cash transfer programme, and Minha Casa Minha Vida, an affordable housing project for low-income families. One Black mother of a child with a disability reported having been on a waiting list of more than five years for Minha Casa Minha Vida<sup>67</sup>.

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<sup>60</sup> Ministério Público do Pernambuco. 2015. Centro de Apoio Operacional de Defesa da Educação. Available at: <https://cao.mppe.mp.br/documents/d/caos/nota-tecnica-n-003-2022-educacao-inclusiva-intersectorialidade-de-politicas-publicas?download=true>

<sup>61</sup> Avery & VNDI. 2023. Projeto das Mães (unpublished study).

<sup>62</sup> Goes, Emanuelle Freitas e Nascimento, Enilda Rosendo do. 2013. Mulheres negras e brancas e os níveis de acesso aos serviços preventivos de saúde: uma análise sobre as desigualdades. Scielo. Saúde em Debate. 2013, v. 37, n. 99, pp. 571-579. Available at: <https://www.scielo.br/j/sdeb/a/kw9SwJT5SHMYty6dhTYvsGg/?lang=pt> Epub 13 Feb 2014. ISSN 2358-2898.

<sup>63</sup> Williamson. 2018. Care in the time of zika: Notes on the ‘afterlife’ of the epidemic in salvador (Bahia), Brazil. Interface: Communication, Health, Education.

<sup>64</sup> Information from Projeto Marias, Rio de Janeiro, 2024.

<sup>65</sup> Avery & VNDI. 2023. The Mothers Project (unpublished study).

<sup>66</sup> Ibid.

<sup>67</sup> Ibid.

38. In October 2021, Ilza Maria Assunção, a 56-year-old black caregiver, died of heart problems at her home in Uberlândia, in the state of Minas Gerais. Her son, Breno dos Reis Gomes de Assunção, 19, who was quadriplegic and dependent on his mother for care, was left without food and died as well.<sup>68</sup>

#### IX. Access to Education - Article 10

39. Black women with disabilities face specific forms of discrimination as a result of intersectional issues across race, gender and disability. Despite representing about 56 per cent of the population with disabilities, Black women with disabilities are the group who are least likely to access public or private education.<sup>69</sup>
40. In 2022, 26.5% of women with disabilities aged 25 or over had completed the basic educational cycle, however, white people with disabilities were more likely than Black and brown people with disabilities to have completed education at 29.7% and 23% on average<sup>70</sup>.

#### X. Access to Work - Article 11

41. A report from IBGE using statistics from the 2019 National Health Survey (PNS) indicate that Black people with disabilities are more likely to be unemployed than white people with disabilities, with Black women with disabilities the most likely to face unemployment at 13.4%, in comparison to Black men with disabilities (8%), white men with disabilities (5.4%) and white women with disabilities (12.6%).<sup>71</sup>
42. A report from IBGE using statistics from the 2019 National Health Survey (PNS) indicate that Black people with disabilities are more likely to be unemployed than white people with disabilities, with Black women with disabilities the most likely to face unemployment at 13.4%, in comparison to Black men with disabilities (8%), white men with disabilities (5.4%) and white women with disabilities (12.6%).<sup>72</sup>
43. Whilst Black people with disabilities are more likely than white people with disabilities to participate in the labour market, they are significantly less likely to be employed in formal labour. Black women with disabilities are the least likely to be formally employed at 40.7%, in comparison to Black men with disabilities (32.6%), white men with disabilities (37.7%) and white women with disabilities (40.7%).<sup>73</sup>
44. Black activists note that hiring processes for formal sector jobs are typically designed for neurotypical white men,<sup>74</sup> which may contribute to the low rates of Black women with disabilities in the formal labour market.
45. Black mothers of children with disabilities report that they have to give up paid work to take on unpaid care work and advocacy to ensure that their children can access their basic rights such as

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<sup>68</sup> Corrêa, Borges. 2021. Corpos de mãe e filho são encontrados em residência no Bairro Tocantins em Uberlândia. O Globo. Available at: <https://g1.globo.com/mg/triangulo-mineiro/noticia/2021/10/13/corpos-sao-achados-em-residencia-no-bairro-tocantins-em-uberlandia.ghtml>

<sup>69</sup> Refer also to: <https://minorityrights.org/resources/the-situation-of-black-people-with-disabilities-in-brazil/>

<sup>70</sup> IBGE. 2023. Pesquisa Nacional por Amostra de Domicílios Contínua.: Pessoas com deficiência 2022.

<sup>71</sup> IBGE. 2022. Available at: <https://agenciadenoticias.ibge.gov.br/agencia-noticias/2012-agencia-de-noticias/noticias/34977-desemprego-e-informalidade-sao-maiores-entre-as-pessoas-com-deficiencia>

<sup>72</sup> IBGE. 2022. Available at: <https://agenciadenoticias.ibge.gov.br/agencia-noticias/2012-agencia-de-noticias/noticias/34977-desemprego-e-informalidade-sao-maiores-entre-as-pessoas-com-deficiencia>

<sup>73</sup> Ibid. Also drawing on situation of Black persons with disabilities in Brazil.

<sup>74</sup> Viegas, L. 2022. Minority and Indigenous Trends 2022: Focus on work.

healthcare and education<sup>75</sup>. The loss of income often puts single parent families, the majority of which are mothers, in precarious economic positions and means that they cannot afford private healthcare plans, which provides better access to some services.

#### XI. **Disaster Risk Reduction – Articles 2 & 3 and General Recommendation 37 (2018)**

46. Black women caregivers and people with disabilities are more likely to live in precarious urban areas that are vulnerable to the impacts of climatic and manmade disasters, such as informal settlements known as favelas, owing to a lack of social assistance and quality housing. Extreme weather events, including heavy rains leading to flooding and landslides, more frequently impact these areas, yet there is very little state assistance available to help mitigate or recover from the impacts, which leaves these families extremely vulnerable.
47. The Data Favela 2023 Survey revealed that the number of favelas doubled in the last decade in Brazil<sup>76</sup>. An estimated 17.1 million people live in favelas, of which 67% are Black, in comparison to 55% of the general population of Brazil<sup>77</sup>. Women are more likely to live in favelas, and an estimated 21% of homes are those of single mothers<sup>78</sup>. Research based on census data shows that Black people in general are significantly more likely to live in areas that are wheelchair inaccessible, and with no or inadequate sidewalks, sanitation, lighting and drainage,<sup>79</sup> which leaves them at particular risk during disasters and emergencies.

#### **Case Study: Flooding in Manguinhos Favela, Rio de Janeiro**

48. The Manguinhos favela is situated in the North of Rio de Janeiro and is home to approximately 36 thousand inhabitants, with a majority of them women<sup>80</sup>. The state fails to provide full coverage of basic services in the area, including water, sanitation, refuse collection and electricity. The area includes two rivers; the Faria-Timbó River and the Jacaré River, and the Cunha canal, all of which are polluted with untreated sewage<sup>81</sup>.
49. Heavy rainfall causes the rivers to regularly overflow into the neighbouring residential areas, endangering the lives of residents, damaging property, preventing mobility and spreading raw sewage that presents a serious public health hazard. According to an urgent report published in 2018 by the Laboratório Territorial de Manguinhos, flooding in the area has become more frequent since the Growth Acceleration Program (PAC) started in December 2009<sup>82</sup>.
50. At least ten families that include women caregivers for family members with disabilities live in Manguinhos, on the edges of the Faria-Timbó river. These women and their families are at extremely high risk from the impacts of flooding and landslides because they are less likely to be able to

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<sup>75</sup> Avery & VNDI. 2023. Mother's Project (unpublished study).

<sup>76</sup> Data Favela. 2023. Um país chamado favela. Accessed from: [https://outraspalavras.net/wp-content/uploads/2023/03/Pesquisa-expofavela\\_datafavela.pdf](https://outraspalavras.net/wp-content/uploads/2023/03/Pesquisa-expofavela_datafavela.pdf)

<sup>77</sup> Ibid.

<sup>78</sup> Ibid.

<sup>79</sup> Boing, A. F., Boing, A. C., & Subramanian, S. V. (2021). Inequalities in the access to healthy urban structure and housing: an analysis of the Brazilian census data. *Cadernos de Saúde Pública*, 37(6). <https://doi.org/10.1590/0102-311X00233119>. Available at: <https://www.scielo.br/j/csp/a/D9SFbBDMsTyf7F5dMfkTjIm/?lang=en>

<sup>80</sup> População. 2010. População em Manguinhos. Accessed from: <https://populacao.net.br/populacao-manguinhos-rio-de-janeiro-rj.html>

<sup>81</sup> Pinho. 2023. Rio on Watch. Available at: <https://rioonwatch.org/?p=73708>

<sup>82</sup> Laboratório Territorial de Manguinhos. 2018. MANGUINHOS PÓS PAC O Agravamento das Enchentes Relato de Urgências. Available at:

[https://www.arca.fiocruz.br/bitstream/handle/icict/47707/RELATO\\_%202018\\_enchentes%2014fev\\_FINAL.pdf?jsessionid=0C7D3A619B7ADBD255E1F8F808DEF1F4?sequence=2](https://www.arca.fiocruz.br/bitstream/handle/icict/47707/RELATO_%202018_enchentes%2014fev_FINAL.pdf?jsessionid=0C7D3A619B7ADBD255E1F8F808DEF1F4?sequence=2)

evacuate quickly. Loss of medicines and assistive devices such as wheelchairs has detrimental impact on the lives of these women and their families.

51. One resident, a Black woman who takes care of her sixteen-year-old daughter who has a physical disability full time, lives on the edge of the Faria-Timbó River in the Manguinhos favela, Rio de Janeiro. At least once a year the river overflows after periods of heavy rainfall and floods the houses of the neighbourhood and houses with sewage water. They do not receive any warning prior to flash flooding and are unable to evacuate beforehand. They have suffered extensive damages including the loss of the daughter's wheelchair and other essential items. No assistance has been received from the state and there have been no improvements in the last sixty years in the situation for families impacted by regular flooding events<sup>83</sup>.

## **XII. Recommendations**

1. Collect, analyse and disseminate data disaggregated by age, disability, colour/race/ethnicity, gender and location alongside performance indicators such as access to healthcare, access to welfare programmes and educational outcomes.
2. Use disaggregated data to inform policy development and implementation to address the issues of intersectional discrimination experienced by Black and indigenous women with disabilities, children with disabilities and women caregivers in consultation with organizations of Black and indigenous people with disabilities and women's organizations.
3. Integrate into public security policies measures to combat the high rates of violence committed against black people with disabilities by the state and public, paying particular attention to addressing those impacted by violence more frequently, such as Black women with disabilities and people with intellectual disabilities.
4. Correct the systematic failure of the Brazilian judiciary to resolve intersectional discrimination experienced by Black and indigenous women with disabilities and resolve the case of Sonia Maria de Jesus.
5. Reinvest in the Unified Health System (SUS), expand health services outside of urban centres and improve transport links between Black and indigenous communities, prioritising the north and northeast regions which experience greater health inequality.
6. Re-design healthcare and social services to be physically, culturally and linguistically accessible to all Black and indigenous communities, paying specific attention to women and girls with disabilities.
7. Ensure that the National Care policy is finalized and implemented as soon as possible, noting specific issues for Black and indigenous women and girls with disabilities and women caregivers and laying out the specifics of how the policy will ensure universal care for this population.
8. Develop public policies to end institutionalization, guaranteeing the right of all persons with disabilities to live with their families or communities, and providing sufficient support for all persons with disabilities and their families to have a dignified life, regardless of their socioeconomic position.
9. Guarantee the right to health and support for Black and indigenous women carers of children with disabilities, to improve their capacity to provide care and reduce the likelihood of institutionalization of their children and negative health impacts of caring.

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<sup>83</sup> Information from Instituto Kevyn Johnson, Projeto Marias. 2024.

10. Revise the eligibility criteria of the BPC disability benefit to de-link it from household income and make it accessible to more people with disabilities and especially Black and indigenous women and girls with disabilities.
11. Implement a non-means-tested support programme to absorb the higher costs of having a disability that reaches women and girls with disabilities and those relying on unpaid familial care within Black and indigenous communities.
12. Implement a targeted awareness raising campaign about women's rights, disability rights and welfare programmes and services within Black and indigenous communities and provide comprehensive support to guide families in accessing welfare programmes and services for women and people with disabilities.
13. Develop and promote public policies for the inclusion of students with disabilities in all spheres and modalities of education from an intersectional perspective, with particular attention to Black and indigenous women and girls with disabilities, seeking not only access, but also the permanence and success of this public, promoting compliance with the legislation regarding the promotion of special education from the perspective of inclusive education.
14. Improve inclusive education practices within schools serving Black and indigenous communities by investing in teacher training, resources, classroom support and sensitisation of schools.
15. Remove the barriers that prevent Black and indigenous women with disabilities and mothers of children with disabilities from entering the formal labour market by implementing public policies that address structural ableism and racism in education, training and work.
16. Develop disaster risk reduction plans, including early warning systems, that prioritise the safety of people with disabilities and their families, with particular attention paid to Black and indigenous women and girls with disabilities.
17. Provide decent housing for people with disabilities, particularly Black and indigenous women and girls with disabilities, so that they are not forced to live in disaster-risk areas.