SUBMISSION TO THE COMMITTEE ON THE RIGHTS OF THE CHILD (CRC)

ALTERNATIVE REPORT FOR THE ADOPTION OF THE LIST OF ISSUES OF

BRAZIL

Children with disabilities belonging to Black and indigenous communities

MINORITY RIGHTS GROUP INTERNATIONAL
VIDAS NEGROS COM DEFICIENCIA IMPORTAM
ACCESSIBILINDÍGENA
INSTITUTO KEVYN JOHNSON – PROJETO MARIAS
INSTITUTO ALANA

Minority Rights Group
International (UK)
Web: www.minorityrights.org
Contact: Lauren Avery,
lauren.avery@minorityrights.org

São Paulo
Brazil
Contact: Luciana Viegas
luciana@vidasnegrascomdeficiencia.org

Acessibilindígena
Brazil
Contact: Siana Guajajara
acessibilindigena@gmail.com

Instituto Kevyn Johnson - Projeto Marias
Tel: +55 997393892
Contact: Norma Maria de Souza
normapsicopedagoga@gmail.com

Instituto Alana
Web: https://alana.org.br/
Contact: Leticia Carvalho Silva
leticia.silva@alana.org

CRC – Committee on the Rights of the Child
98 Pre-Sessional Working Group (May 27, 2024 - May 31, 2024)
CONTENTS

1. Co-submitting organizations
2. Methodology
3. List of key issues relating to clusters of rights to be included in the List of Issues

1. CO-SUBMITTING ORGANIZATIONS

Minority Rights Group International 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.

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

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

Instituto Alana - Civil Society Organization that works to promote the rights of children and adolescents and promotes litigation, advocacy and communication actions at national and international levels with a focus on children from the Global South.

2. METHODOLOGY

The data presented in this report was collected and analysed by the co-submitting organizations, including organizations of Black people and indigenous people with disabilities, organizations of mothers of children with disabilities, organizations defending children’s rights and community organizations in favelas that serve children with disabilities and their families. 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 children with disabilities and their families.

Children with disabilities and their families belonging to Black and indigenous communities based on disability, race/ethnicity/colour, language, gender, culture and other identity factors face multiple, intersecting and aggravated forms of discrimination that cannot be separated and therefore need to be highlighted and addressed by relevant bodies and organizations at local, national and international levels.

---

1 Data sources included official government statistical databases, national surveys, a review of Civil Society Organizations (CSOs) databases, and research reports. In addition, interviews and visits were carried out in 2022 and 2023 in the states of São Paulo, Rio de Janeiro, Minas Gerais, Pernambuco and Rio de Janeiro carried out by members of VNDI, MRG and the University of York through the Project Highlighting Intersectional Discrimination by Human Rights Mechanisms and the Mothers Project. Data was collected from people with disabilities and their families from various marginalized communities and groups, institutionalized children and adults, quilombola communities, people experiencing homelessness and those in the justice system and involved consultations with local and national organizations of people with disabilities (OPDs), services for people with disabilities, government organizations (GOs) and non-governmental human rights organizations (NGOs).
In this report, ‘Black’ is used to refer to those who declare themselves black (preto) 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 communities in Brazil.

3. LIST OF KEY ISSUES RELATING TO CLUSTERS OF RIGHTS

a. General principles - non-discrimination (Art. 2) and right to life, survival and development (Art. 6); and
Disability, basic health and well-being - measures taken to ensure dignity, self-sufficiency and active participation in the community for children with disabilities (Art. 23)

i. Lack of disaggregated data

The lack of published disaggregated data that includes race, disability and age makes estimating official numbers of Black and indigenous children with disabilities 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, nor did it include data on children. Linked to this lack of publicly available disaggregated data, there is a lack of specific policies developed to meet the needs of Black and indigenous children with disabilities, who are often underserved or missed by general policies directed at children, children with disabilities or Black and indigenous adult populations. Data about indigenous children with disabilities is particularly scarce and underreported which makes it even difficult for them to access basic services and creates barriers to the development of policies and programmes to reach this population.

Recommendations and Questions:

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 children with disabilities and their families in consultation with organizations of Black and indigenous people with disabilities, including children.

ii. Lack of access to health services

Lack of access to health services in Brazil impedes the right of Black and indigenous children with disabilities to dignity, right to life, self-sufficiency and active participation in their communities, yet there is a lack of scientific research showing specific health outcomes for this population. 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

---

2 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
4 Information from Accessibilindígena. 2024.
Black populations also have poorer access to high complexity (specialized) health services\textsuperscript{16}, due to the location concentration of these services in urban centres, which are dominated by the white population\textsuperscript{17}. 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. 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\textsuperscript{18}. Long waiting times for overstretched SUS services disproportionately impact Black and indigenous children with disabilities, owing to their poorer access to private healthcare. Children with Congenital 


\textsuperscript{8} Information from Accessibilindígena. 2024.


\textsuperscript{10} ibid.


\textsuperscript{13} ibid.


\textsuperscript{15} ibid.


\textsuperscript{8} Information from Accessibilindígena. 2024.


\textsuperscript{10} ibid.


\textsuperscript{13} ibid.


\textsuperscript{16} 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.

\textsuperscript{17} Instituto de Pesquisa Econômica Aplicada (Ipea). 2021. DESIGUALDADES RACIAIS E DE RENDA NO ACESSO À SAÚDE NAS CIDADES BRASILEIRAS. Accessed from: https://repositorio.ipea.gov.br/bitstream/11058/11454/1/td_desigualdades_raciais_renda_publicacao_preliminar.pdf

\textsuperscript{18} Avery & VNDI. 2023. Projetos das Mães (unpublished study).
Zika Syndrome (CZS), of whom eight out of ten were born to Black mothers\(^\text{19}\), have had to wait months or years for lifesaving or life-improving spinal surgeries or other interventions\(^\text{20}\). 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\(^\text{21}\).

Black people 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\(^\text{22}\). 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\(^\text{23}\). Other mothers of children with disabilities in the same study reported waiting years for their child’s disability diagnosis via the SUS, due to bureaucracy, discrimination and long waiting lists, which left children without access to therapies and healthcare vital to their development\(^\text{24}\). Mothers also reported that their children lost their access to healthcare services, such as physical and occupational therapies, during the Covid-19 pandemic and still remain without access\(^\text{25}\). For instance, one mother who refused to take her clinically vulnerable son to his physio appointments because they were not implementing Covid-safe measures then lost their place, and now is at the back of the queue again.

**Recommendations and Questions:**

1. *How does the Government of Brazil plan to investigate and remove the specific barriers facing Black and indigenous children with disabilities to access quality, timely and affordable healthcare?*

2. *Reinvest in the SUS, expand health services outside of urban centres and improve transport links between Black and indigenous communities. Re-design services to be physically, culturally and linguistically accessible to all Black and indigenous communities.*

iii. *Lack of access to education*

Inequality in access to education is amplified for Black children with disabilities, owing to intersectional discrimination on grounds of race and disability. IBGE data indicates that Black children with disabilities aged 15 to 17 are less likely to be in school than their white counterparts (83.7% and 86.4%, respectively), although enrolment rates for younger children were more equitable, indicating higher school dropout rates for Black children with disabilities than for white children with disabilities\(^\text{26}\). Research indicates that exposure to double stigma has negative impacts on the self-esteem and ability to learn for Black children with disabilities\(^\text{27}\). Denial of school places and inadequate support in classrooms is also cited as a key barrier to education for children with disabilities\(^\text{28}\).

---

\(^{19}\) Center for Reproductive Rights. 2018. Unheard Voices: Women’s Experiences With Zika, Brazil.

\(^{20}\) Information from Mães de Anjos. 2024.


\(^{22}\) VNDI. 2022. Experience reports collected from VNDI members in 2022.


\(^{24}\) ibid.

\(^{25}\) ibid.


Children with CZS also face significant barriers to education which undermines their development and right to active participation in their community. Research on access to education for children with CZS revealed that barriers included physical inaccessibility of school buildings and a lack of professional knowledge of teachers on inclusive education practices for children with CZS. One local NGO in the northeast of Brazil responded to the denial of entry to children with CZS into local schools by launching a sensitization project that aimed to help teachers understand the needs of children and implement inclusive education practices. The project was successful in improving school acceptance rates but stopped due to lack of funding.

Indigenous disability activists report that inclusive education does not exist within indigenous territories. Whilst there is some political will to create and implement policies to address the lack of education for indigenous children with disabilities, the biggest barrier is the lack of data and research on the topic.

**Recommendations and Questions:**

1. Develop and promote public policies for the inclusion of students with disabilities in all spheres and modalities of education from an intersectional perspective, 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.
2. Improve inclusive education practices within schools serving Black and indigenous communities by investing in teacher training, resources, classroom support and sensitisation of schools.
3. What actions has the Brazilian State adopted to ensure the application of inclusive education throughout the national territory, in accordance with the Convention on the Rights of the Child, the Convention on the Rights of Persons with Disabilities, the Convention on the Elimination of Discrimination and the Declaration on the Rights of Indigenous Persons?

iv. Lack of access to disability diagnosis and welfare programmes

Barriers to accessing healthcare directly impact the ability of Black and indigenous children with disabilities to access a disability diagnosis, which is a prerequisite to access to disability-related benefits, such as the Continued Pension Benefit (BPC), administered via the National Social Security Institute (INSS). The BPC is equivalent to one minimum wage, which was set at 1,212 BRL (approx. 244 USD), an amount that is woefully inadequate to absorb the extra costs associated with disability and the loss of paid work to take care of a child. Access is also limited to families with a total income equal to or less than a quarter of the minimum wage (approx. 58.75 USD) per capita/month, and so only reaches a small minority of families who require support.

Issues accessing the BPC include poorer access to INSS offices outside of urban centres, barriers to access relating to documentation and medical diagnosis and inconsistency in evaluating eligibility and barriers to access to information about the scheme itself. Access issues disproportionately impact

---

32 Information from Accessibilindígena. 2024.
Black and indigenous communities, who are less likely to live in urban centres and are more likely to have lower levels of education and income. In a recent study of a cohort of 77 caregivers of children with disabilities, 22% reported that their child had previously been denied a disability diagnosis but for Black children reported rates were higher at 27% comparatively to white children at 10%35. Black mothers also report having requests for BPC denied on the grounds that there was already a family member receiving BPC in the family which goes against the legal provision.36

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 Vida37. Interviews with centre managers and healthcare workers serving children with disabilities reported that a lack of information about welfare services but also a lack of assistance in navigating bureaucratic systems was a particular barrier within poor Black and favela communities38.

**Recommendations and Questions:**

1. Revise the eligibility criteria of the BPC to de-link it from household income and make it accessible to more people with disabilities.
2. Address issues of racial bias in eligibility evaluation processes for welfare programmes.
3. Implement a non-means-tested support programme to absorb the higher costs of having a disability.
4. Implement a targeted awareness raising campaign about disability rights and welfare programmes within Black and indigenous communities and provide comprehensive support to guide families in accessing programmes.

**b. Family environment and alternative care - separation from parents (Art. 9) and children deprived of a family environment (Art. 20)**

i. Institutionalization

Current national data on the race and age of people with disabilities in institutions is not publicly available. However, there is evidence to suggest that Black children with disabilities are more likely to be deprived of a family environment by being placed under state care and are therefore overrepresented in institutional settings. For example, a study in the state of Rio de Janeiro showed that of 112 children living in segregated institutions for children with disabilities, 66.9% were Black and 29.5% were white. The same study showed that of 61 children with disabilities living in mixed (non-segregated) institutions, 67.3% were Black and 29.5% were white.39 This is in comparison to the general population of Rio de Janeiro identifying as Black at 51.7% and white at 47.4%.40

Additionally, observations by members of VNDI and MRG during visits to inclusive residences in São Paulo and Rio de Janeiro in 2022, analysis of photographic and video evidence from institutions,

---

36 Information from Instituto Kevyn Johnson – Projeto Marias. 2024.
37 ibid.
38 ibid.
interviews with researchers and institution staff suggest that Black children with disabilities are vastly overrepresented in institutional settings41.

A 2018 research project by Human Rights Watch showed that violations of rights regularly occurred in institutional settings for children with disabilities in Brazil, including restraining, guardianship (deprivation of legal capacity), medication without consent, and lack of access to education42. This is reflected in the findings of the same Rio de Janeiro study, which found that in the segregated institutions, 81.3% of the children with disabilities were illiterate, and 10.7% had not completed elementary level education and in the mixed institutional settings, 32.8% were illiterate and 55.7% had not completed elementary level education43.

ii. Lack of care policy and family support

The absence of a national care policy that would provide remuneration for care work and lack of family support is likely to be a key factor contributing to the high rates of institutionalization of Black children with disabilities in Brazil and deprivation of their right to a family environment44. However, it is positive that there are currently steps being taken to implement a national care policy including public consultation and involvement of the Ministry of Racial Equality, the Ministry of Indigenous Peoples and the Ministry of Women45.

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 five46. Whilst there is no official data disaggregated by race, some mothers of children with disabilities interviewed in a 2023 study estimated that paternal abandonment rates within Black families is as high as 90%47.

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 step down work to take care of their child.

Black women in Brazil are already more likely to face barriers to accessing preventative healthcare owing to institutional racism.\textsuperscript{48} 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, which provides little to no\textsuperscript{49,50}. Currently, there is no prioritization of healthcare access for carers of children with disabilities in Brazil, which compounds the issues this group already experiences in accessing healthcare and has negative impacts on the health and wellbeing of children with disabilities reliant on their care.

**Recommendations and Questions:**

1. Ensure that the National Care policy is finalized and implemented as soon as possible, noting specific issues for Black and indigenous children with disabilities and their families and laying out the specifics of how the policy will ensure universal care for this population.
2. 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.
3. 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.

**c. Violence against children** - sexual exploitation and sexual abuse (Art. 34) and abuse and neglect, including physical and psychological recovery and social reintegration (Arts. 19 and 39)

i. Sexual violence and violence against children and adolescents with disabilities

According to UNICEF and Forúm Brasileiro de Segurança Pública, there is a general underreporting of the race/colour of child victims of lethal violence and rape, where it was only recorded in 41% of cases between 2017 and 2020\textsuperscript{51}. Where race/colour was recorded, it shows a steady increase in victims of these crimes being Black children across all age groups\textsuperscript{52}. Rape of vulnerable persons, which according to Art. 217-A of the Penal Code includes children under 14 years of age, those with an illness or mental disability, or whose resistance capacity is reduced, rose by 8.6% in 2022\textsuperscript{53}. Yet data collected does not comprehensively include disability indicators, resulting in a lack of data on how many children with disabilities are victims disaggregated by race/colour.

**Recommendations and Questions:**

1. How does the Government of Brazil plan to improve the data collection on sexual abuse and violence against children with disabilities to include more accurate data collection on race/colour?
2. How does the Government of Brazil plan to protect all children with disabilities from instances of sexual abuse and violence and hold perpetrators accountable?

---


\textsuperscript{49} Williamson. 2018. Care in the time of zika: Notes on the ‘afterlife’ of the epidemic in salvador (Bahia), Brazil. Interface: Communication, Health, Education.

\textsuperscript{50} Information from Projeto Marias, Rio de Janeiro, 2024.


\textsuperscript{52} ibid.