



# UNHEARD VOICES

WOMEN'S EXPERIENCES WITH ZIKA

# BRAZIL

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RIGHTS

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## WOMEN'S EXPERIENCES WITH ZIKA


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# Glossary

**Adolescents:** People between the ages of 10 and 19 as defined by the World Health Organization (WHO).

***Aedes Aegypti*:** A mosquito that can spread dengue, chikungunya, Zika, and Mayaro viruses as well as yellow fever and other diseases.

**American Convention on Human Rights (ACHR):** A regional convention that promotes and protects human rights in the Americas, which was adopted in San Jose, Costa Rica on November 22, 1969 (also known as the Pact of San Jose).

**Centers for Disease Control and Prevention (CDC):** The leading national public health institute of the United States.

**Congenital Zika Syndrome (CZS):** A pattern of complications unique to fetuses and infants infected with the Zika virus before birth. It is defined by five features: (1) severe microcephaly in which the skull has partially collapsed; (2) decreased brain tissue with a specific pattern of brain damage, including subcortical calcifications; (3) damage to the back of the eye, including macular scarring and focal pigmentary retinal mottling; (4) congenital contractures, such as clubfoot; and (5) hypertonía restricting body movement soon after birth.

**Convention on the Elimination of All Forms of Discrimination against Women (CEDAW):** An international treaty upholding the human rights of women that was adopted in 1979 by the United Nations General Assembly (see definition below), which is often described as an international bill of rights for women.

**Convention on the Rights of People with Disabilities (CRPD):** A convention and optional protocol intended to protect the rights and dignity of people living with disabilities that was adopted on December 13, 2006 by the United Nations General Assembly (see definition below) and is ratified by 174 countries.

**Convention on the Rights of the Child (CRC):** An international treaty upholding the human rights of children that was adopted by the United Nations General Assembly (see definition below) on November 20, 1989. It is the most widely ratified treaty in the world (195 countries).

**Endemic:** A disease that exists permanently in a region or population.

**Epidemic:** An outbreak of a disease that attacks a large number of individuals within a population at the same time and has the potential to spread through one or several communities.

**General Comment/Recommendation:** A comprehensive interpretation of an article of a treaty issued by the respective U.N. Treaty Monitoring Body (see definition below).

**Guillain-Barré Syndrome (GBS):** A condition in which the immune system attacks a person's nerves.

**Human Development Index (HDI):** A composite statistic of life expectancy, education, and per capita income indicators that is used to rank countries into four tiers of human development.

**Inter-American Commission on Human Rights (IACHR):** An autonomous organ of the Organization of American States (OAS; see definition below), which was created to promote the observance and defense of human rights in the Americas. Its mandate is found in the charter of the OAS and the American Convention on Human Rights.

**Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (IACEDAPD):** A regional instrument committed to eliminating discrimination in all its forms and manifestations against persons with disabilities that was adopted on June 7, 1999.

**Inter-American Convention on the Prevention, Punishment, and Eradication of Violence against Women (IACPEVAW):** A convention that was adopted in 1994, which codifies a state's duty to prevent, punish, and eliminate violence against women in the Americas (also known as the Convention of Belém do Pará).

**Inter-American Court on Human Rights (the Court):** An international court operating under the auspices of the Organization of American States, which derives its mandate from the American Convention on Human Rights. It began operating in 1979 and has seven independent judges. Among other things, the Court hears complaints against states and rules on specific cases of human rights violations.

**International Convention on Economic, Social, and Cultural Rights (ICESCR):** A multilateral treaty adopted by the United Nations General Assembly (see definition below) on December 16, 1966, which has been ratified by 165 countries.

**International Health Regulations (IHR):**

An international legal instrument that is binding to 196 countries across the globe, including all member states of the World Health Organization (see definition below).



**International Law:** The body of legal rules and norms that are decided and enforced by nation states at the international level based on treaties, customary law, and general principles of law.

**Microcephaly:** A congenital malformation resulting in a smaller than normal head size at birth or that develops within the first few years of life. This condition has also been associated with other birth defects and neurologic conditions, such as Congenital Zika Syndrome.

**Non-governmental Organization (NGO):** A nonprofit organization that is independent of governments and international governmental organizations.

**Office of the United Nations High Commissioner for Human Rights (OHCHR):** A U.N. agency that works to promote and protect human rights that are guaranteed under international law.

**Organization of American States (OAS):** An intergovernmental body composed of 35 countries in the western hemisphere. All members must ratify the Charter of the OAS, which is to strengthen cooperation and advance common interests, including democracy and human rights.

**Pan American Health Organization (PAHO):** An international public health agency working to improve the health and living standards of the people of the Americas.

**Pandemic:** An epidemic that spreads globally.

**Public Health Emergency of International Concern (PHEIC):** A formal declaration by the World Health Organization (see definition below) Emergency Committee operating under International Health Regulations, which designates a public health crisis of potential global reach (referred to as a “global health emergency” throughout this report).

**United Nations (U.N.):** An intergovernmental organization established to promote international cooperation and create and maintain international order.

**United Nations Children’s Fund (UNICEF):** A U.N. agency that works to protect and defend the rights of every child.

**United Nations Development Programme (UNDP):** A U.N. agency that works to eradicate poverty and reduce inequalities through sustainable development.

**United Nations General Assembly:** The General Assembly is one of the six main organs of the U.N., the only one in which all Member States have equal representation. All 193 Member States are represented in this unique forum to discuss and work together on a wide array of international issues covered by the U.N. Charter, such as development, peace and security, international law, etc.

**United Nations Human Rights Council:** An intergovernmental body within the United Nations that is made up of 47 states responsible for the promotion and protection of all human rights around the globe.

**United Nations Population Fund (UNFPA):** A U.N. agency dedicated to financing and supporting population and reproductive health programs in low- and middle-income countries.

**Universal Declaration of Human Rights (UDHR):** A declaration adopted by the United Nations General Assembly (see definition below) on December 10, 1948, consisting of 30 articles that define the meaning of fundamental human rights appearing in the United Nations Charter, which is binding for all member states.

**U.N. Special Rapporteur:** An independent expert appointed by the United Nations Human Rights Council (see definition above) to investigate, monitor, and recommend solutions to human rights problems. This person is not financially compensated.

**U.N. Treaty Monitoring Bodies (UNTMB or TMB):** U.N. committees that monitor governmental compliance with the major U.N. human rights treaties. While TMBs are not judicial bodies, they influence governments by issuing specific political observations about a state’s progress and compliance with human rights obligations. They also issue general recommendations, which are not specific to any one country but provide specific guidance on how states can better implement a provision or provisions of a treaty. In certain circumstances, some TMBs also have a mandate to decide state responsibility for individual complaints of violations.

**World Health Organization (WHO):** A U.N. agency devoted to researching and promoting public health worldwide.

**Vector:** An organism, typically a biting mosquito or tick, that transmits a disease or parasite from one animal or plant to another.

**Zika Virus:** An arbovirus that typically presents with mild symptoms such as fever, headache, rash, and muscle or joint pain typically lasting from two to seven days, however, it can also be asymptomatic. Zika is primarily transmitted through a daytime-active *Aedes aegypti* mosquito found in tropical regions. The virus can also be transmitted through sexual intercourse and during pregnancy from a woman to the fetus. To date, there is no specific treatment or vaccine available for Zika.



# Foreword

The goal of this report series is threefold: firstly, it presents and evaluates the diverse impact that the Zika virus has had on the reproductive lives of women living in Brazil, Colombia, and El Salvador. Secondly, these reports analyze the global response to the Zika epidemic through both a public health and human rights lens, ultimately finding that there was a disconnect between the global, national, and local policies addressing the crisis and the realities faced by women, their children, families, and caregivers. Finally, through the personal stories of women affected by Zika, these reports underscore the gendered nature of the epidemic and the disproportionate effect the epidemic has had on girls and women throughout Latin America and the Caribbean.

Nearly a year after public health experts first raised the alarm about the Zika outbreak, a multidisciplinary team of human rights and public health experts from the Center for Reproductive Rights (the Center), Harvard T.H. Chan School of Public Health's Women and Health Initiative (W&HI), and Yale's Global Health Justice Partnership (GHJP) began using an interdisciplinary approach to research the epidemic.

We interviewed a diverse group of stakeholders, all of whom were familiar with or involved in the national, regional, and global response to the Zika epidemic. Our interviewees come from a diverse range of backgrounds in research and academia, the media, the health care sector, local and national governments, international organizations, and civil society.<sup>1</sup> Most critical to our research, however, were the interviews conducted with women who had been directly affected by the virus—those living with Zika, at-risk of contracting Zika, or who had decided to continue with a pregnancy after having been infected with Zika. This report series seeks to bring their voices to the forefront of the discussion on the Zika epidemic so that their experiences can inform future debates around global responses to public health crises.

This investigation is unique in that it integrates both a public health and human rights framework in the analysis of the Zika epidemic. This two-pronged approach provides a more holistic understanding of the Zika crisis and highlights the role that structural inequality has had on fueling the epidemic and amplifying its impact, particularly in regard to a woman's right to exercise informed and autonomous decision-making.



# Executive Summary

In April 2015, the first signs of Zika virus hit Brazil. As of November 2017, over 369,013 suspected and confirmed cases have been reported,<sup>2</sup> including 1,845 confirmed cases of Congenital Zika Syndrome (CZS) in babies.<sup>3</sup> The majority of these reported cases occurred among women, particularly women of reproductive age.<sup>4</sup>

In February 2016, the World Health Organization (WHO) came out with a public statement declaring the Zika epidemic a Public Health Emergency of International Concern (PHEIC).<sup>5</sup> The WHO and U.S. Centers for Disease Control (CDC) followed this announcement by advising pregnant women against traveling to the more than 45 countries where Zika was present, getting tested if they had traveled to these regions, and refraining from having unprotected sex with partners who had visited these regions.<sup>6</sup> Despite these initial broad preventive measures, as of March 2017, over 70 countries and territories have reported evidence of mosquito-borne Zika transmissions.<sup>7</sup>

In November 2016, as the number of Zika cases decreased, the WHO declared an end to the epidemic's international emergency status. However, some public health experts worried that losing this emergency status would deprioritize state efforts to effectively and efficiently respond to the epidemic.<sup>8</sup> In response to this concern, Dr. Peter Salama, executive director of the WHO Health Emergencies Programme, said, "We are not downgrading the importance of Zika. We are sending the message that Zika is here to stay and the WHO response is here to stay."<sup>9</sup> Nevertheless, despite the WHO's clarification, that was not how the message was interpreted by governments in Zika-affected countries. By May 2017, the Brazilian government had also declared that the national public health emergency had ended.<sup>10</sup>

Evidence suggests that the WHO and Brazilian government's retraction of the epidemic might have been issued too soon. In fact, the number of infected people demonstrates an ever-growing epidemic. The long-term impact of the virus remains poorly understood, and the experiences of women and their families continue to be ignored by governments and health authorities.

## What are the consequences of Zika?

Zika is primarily spread by an infected *Aedes* species mosquito, but can also be sexually transmitted or passed from a pregnant woman to her fetus. A fetus infected with Zika can develop prenatal complications, such as microcephaly and/or Congenital Zika Syndrome. To date, there is no vaccine or medicine available to prevent or treat Zika, and diagnostic testing tools remain inconsistently implemented across infected regions.<sup>11</sup>

The medical community continues to explore the repercussions of Zika around the world and have found that in addition to microcephaly, there have been other reported complications in Zika-affected children. For example, children may experience muscle and joint seizures, which prevents them from moving and maintaining balance, or they may experience developmental delays, vision and hearing alterations, or clubfeet.<sup>12</sup> These complications can range from mild to severe, and can even be life-threatening.<sup>13</sup> Because it is difficult to predict at birth what problems a baby may develop from microcephaly, it is important for these children to be closely monitored by a trained health care professional during the first few years of their lives.<sup>14</sup> Unfortunately, to date, there is no known cure or standard treatment for Zika-related complications.<sup>15</sup>

The Brazilian government's response to the epidemic showed a lack of consideration for the experiences of women infected with Zika and their children born with disabilities as a result of the virus. Although the



government consistently advised women to delay pregnancy and worked to devise mosquito control strategies to mitigate the spread of the virus, this approach did not adequately integrate a human rights perspective and thus did little to ameliorate complications resulting from the epidemic.

Many public health experts interviewed for this report criticized Brazil's prioritization of vector control as a means of managing the spread of Zika as it suppressed other preventative strategies, such as comprehensive sexual and reproductive health services, social protections for children with disabilities, and improved water and sanitation infrastructure.

Recommendations for how to deal with Zika also varied depending on the audience. While tourists from Global North countries were advised not to travel to Latin American countries with reported Zika cases, impoverished women living in infected areas in Brazil were simply instructed to avoid getting pregnant.<sup>16</sup> These warnings, however, were not accompanied by adequate health care information or services that would enable women to make informed choices about their reproductive health. Rather than receiving the tools necessary to navigate the epidemic, women in Brazil were frequently met with violence, stigma, or criminalization when seeking out reproductive health services, if they were available at all.<sup>17</sup>

## Our Findings

The link between Zika and a woman's sexual and reproductive rights was not lost on public health officials. Shortly after the WHO declared Zika a global health emergency, the importance of sexual and reproductive rights in the global response to the epidemic was affirmed by the United Nations Population Fund, the U.N. High Commissioner on Human Rights, and the Inter-American Commission on Human Rights.<sup>18</sup> However, our research indicated that language affirming a woman's sexual and reproductive rights was largely absent from Zika-related public health campaigns or government responses in Brazil, showing a critical disconnect between the global and national response. In fact, our research found that women navigating the Zika epidemic in Brazil encountered many barriers in exercising their sexual and reproductive rights and that crosscutting gender norms and inequities placed serious limitations on options for low-income women living in remote and rural areas.

## Family Planning and Information Access

A woman's ability to control family planning was a critical challenge in responding to the threats posed by Zika. For example, cost was often flagged as a barrier to accessing contraception and lengthy travel distances to clinics were also highlighted as making access to sexual and reproductive health services difficult, if not impossible. In northeast Brazil, where our interviews were conducted, women had to pay for contraception out of pocket because they were not aware that they could access contraception through the public health system, signaling a major communication failure pertaining to disseminating reproductive health information to women.<sup>19</sup> Most of the women we interviewed stressed that the responsibility to avoid pregnancy fell disproportionately on their shoulders over their male partners.

Numerous interviewees also reported a lack of clarity in government messaging regarding Zika. In fact, many women shared how they were often unsure, or even unaware, of the risks associated with Zika. For instance, two of the five women we interviewed in Brazil did not know that Zika could be transmitted sexually.<sup>20</sup> In addition, we found that doctors were also struggling to provide patients with accurate and unbiased information regarding Zika-related pregnancy complications.<sup>21</sup>





## Abortion Access

Even in situations where abortion is legal, it is not always easy for women to access abortion services. Health care professionals frequently deny care based on personal, religious convictions in what is an improper use of their right to freedom of religion. Women often reported how physicians would abstain from mentioning abortion, claiming that their personal feelings were sufficient justification for not sharing this information with patients. Women seeking follow-up care after obtaining clandestine abortions were often met with hostility and threats despite clear guidance from the Ministry of Health mandating the contrary.<sup>22</sup> In many instances, health care professionals were too fearful or apprehensive to provide abortion care due to their personal or religious beliefs, fears of being prosecuted, or a combination of the two. The stigma surrounding abortion, however, did not dissuade women from seeking this option. In fact, since Zika's declaration as a public health emergency, Women on Web, an organization that provides information on medical abortions, reported an increase of abortion requests from 36% to 106% in the northeast region of Brazil.<sup>23</sup>

## The Rights of Children with Disabilities

Social inclusion and access to support mechanisms were some of the largest concerns of families with children with disabilities. These families were typically among the most socioeconomically disadvantaged, making the added responsibility of taking care of a child with special needs even more difficult. In countries without universal health coverage and integrated social welfare support systems, we found that children with disabilities and their caretakers were particularly vulnerable.

## The Economic and Social Rights of Women, Families, and Children

As with many other infectious diseases, the spread and impact of Zika is tied to social and economic inequalities in the Americas.<sup>24</sup> The WHO has noted that “the burden of Zika falls on the poor...in tropical cities throughout the developing world, the poor cannot afford air-conditioning, window screens, or even insect repellent.”<sup>25</sup> Additionally, accessing reproductive health services, such as contraception and abortion, is more difficult for those who face socioeconomic marginalization.

During on-site visits in the Brazilian state of Bahia, we saw untreated open sewage and storm drains that were creating unsanitary standing water conditions near the communities of women we interviewed. Our research found that the lack of government investment in water and sanitation infrastructure contributed to conditions that increased the proliferation of mosquitos, which quickened the spread of Zika.

We also found that in almost all cases women were the main caregivers of children born with Zika-related disabilities. We documented the stories of women who had to quit their jobs or were no longer able to study because of how time consuming it was to take care of their children. Women also often reported needing to travel hours to take their children to therapies and shared how they struggled to access medicines, treatment, and the medical equipment needed to take care of their children.

# Government's Human Rights Obligations

At the bare minimum, a human rights-based approach to the Zika virus requires:



access to quality and comprehensive information about the virus, its risks, and the options available regarding reproductive health to guarantee informed and autonomous decision-making



access to comprehensive reproductive health services, including contraception, quality maternal health, and abortion services



the provision of reasonable accommodations, including welfare plans, that guarantee the full inclusion and development of children with disabilities, which in turn will ease the added responsibility on families and caregivers



the protection of the right to an adequate standard of living through the provision of access to sufficient, safe, acceptable, physically accessible, and affordable water for personal and domestic use

The Brazilian government's advice instructing women not to get pregnant as a means of navigating the Zika epidemic was problematic and raised human rights concerns. Governments cannot advise women to avoid or delay a pregnancy without considering the availability and accessibility of reproductive health care services that would allow them to exercise this control over their lives and bodies. Furthermore, placing the burden of contraception on women alone perpetuates the stereotype that only they are responsible for planning or preventing a pregnancy.

In addition to contraception, governments must ensure that women, children with disabilities, and their caretakers have reasonable access to educational, health, financial, and other social accommodations. However, our research found that a disability rights perspective was rarely considered by governments in affected areas despite the spike in children born with Zika-related complications.

Brazil is a state party with a number of international human rights treaties that protect women's fundamental rights, the rights of people with disabilities, the right to water and sanitation, and the right to the highest attainable standard of health, among other socioeconomic rights. Under international human rights law, countries are required to prioritize women's autonomy and self-determination by ensuring their right to comprehensive reproductive health information and services.<sup>26</sup> Brazil also has an obligation to provide the support, training, and services necessary for raising a child with a disability.<sup>27</sup> As established in the Brazil Constitution, the rights contained in the country's constitution do not exclude those that are provided under international treaties.<sup>28</sup> Therefore, as a signatory of these international and regional instruments, Brazil must work to respect, protect, and fulfill these human rights.<sup>29</sup>

## Conclusion

The Zika epidemic in Latin America exposed the stigmatization of reproductive rights within Brazil and highlighted the need for contraception and access to safe and legal abortion as a means of family planning. Zika not only exacerbated the need for these rights in the countries that it impacted, but also laid bare existing inadequacies and inequities in laws both as they were written and executed.

Unfortunately, our research found few signs that lasting changes were being made in Brazil to address the shortcomings of their health care systems to adequately protect women's reproductive health and the rights of people with disabilities. While the unmet needs of children with disabilities will surely be the longest lasting impact of Zika's many consequences, unfortunately this has not been a focus of the government's response to the epidemic.

Although there remains the possibility that positive law and policy changes could emerge as the government and their citizens reflect on the Zika epidemic and its impact, this seems increasingly unlikely given that the stories detailed in this report highlight the limited extent that women's perspectives were taken into consideration during the outbreak. Through their testimonies, it has become apparent that the Brazilian government did not adequately ensure that women had the necessary tools to make informed decisions about their reproductive lives nor were they provided with the resources to take care of their children born with Zika-related complications, which further exacerbated existing inequalities.



# Methodology

In March 2017, we conducted interviews with five women from the city of Salvador in Bahia, a region of Brazil that had been highly affected by the Zika virus.<sup>30</sup> The five women lived in Subúrbio Ferroviário, a low-income area that had been particularly affected by the epidemic. The women we interviewed ranged in age from 22 to 36 years old and included two women who had been pregnant in early 2016; a woman who had been infected with Zika and postponed getting pregnant; a woman who planned to become pregnant in the near future; and a woman who did not want to become pregnant in the near future.

Between February and May 2017, interviews were also conducted with 27 key stakeholders in Salvador and other areas of Brazil. These included seven interviewees from academic or government research, two interviewees from the media, five interviewees from the health care system, seven interviewees from the government, three interviewees from U.N. agencies, and four interviewees from civil society. Interviewees included representatives from, among other entities, the federal Ministry of Health, the Bahia and Salvador Secretariats for Health, the Oswaldo Cruz Foundation, the United Nations Population Fund, and a local support organization for families affected by Zika.

Brazil is a very large and diverse country. As a result, the Zika epidemic unfolded differently in the various affected regions. Due to Brazil's federal system, states had tremendous autonomy in determining and implementing their response to the epidemic. In this report, the majority of our fieldwork was focused on the region of Bahia, making most of our analysis relevant specifically to this region's experience and policies, which were not necessarily representative of other state responses to the epidemic. However, while our research does not provide an in-depth analysis and comparison of responses across all affected states in Brazil, it does draw on research and interviews relating to other states and regions, giving a more national outlook to the problem.

Researchers complied with the Lund-London Guidelines on fact-finding reports by non-governmental organizations and completed the Protecting Human Research Participants training program offered by the U.S. National Institutes of Health's Office of Extramural Research. Informed consent was obtained from each interviewee and all data and information was securely recorded and stored. This research received Institutional Review Board (IRB) approval applicable to Yale School of Public Health and Yale Law School students and fellows in conjunction with the NGO compliance.



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# Background

Brazil was the first country in the region to experience an outbreak of the Zika virus in Latin America, and continues to have the largest number of reported cases.<sup>31</sup> Since the first cases of Zika were confirmed in the northeastern state of Bahia in April 2015, the virus has spread to all of Brazil's 27 federal states.<sup>32</sup> The epidemic peaked in early February 2016,<sup>33</sup> and as of November 2017 there have been over 369,013 suspected and confirmed cases.<sup>34</sup> Most reported cases have occurred among women, particularly women of reproductive age.<sup>35</sup> There have also been nine deaths among those infected with Zika in Brazil—the highest number of any infected country<sup>36</sup>—and 1,845 confirmed cases of Congenital Zika Syndrome (CZS) in babies.<sup>37</sup>

As the largest country in Latin America, Brazil has a racially and ethnically diverse population of over 200 million people. More than half of Brazilians (and nearly 75% of those in the north and northeast where the Zika epidemic was most prevalent) self-identify as afro-descendants.<sup>38</sup> Bahia, the northeastern state where the first cases of Zika were reported, is predominately Afro-Brazilian,<sup>39</sup> and Salvador, a city in Bahia where most of the interviews for this study were conducted, is one of the municipalities with the highest number of people who identify as Black or *pardo* (mixed race).<sup>40</sup> Statistics released by the Brazilian Ministry of Health confirmed that women of color were most affected by Zika, detailing that eight out of ten babies born with microcephaly or other Zika-related complications were born to Afro-descendant or multiracial women.

Northeastern Brazil is one of the poorest regions of the country and economic inequality is largely among ethnic minorities.<sup>41</sup> Bahia, the state in which Salvador is located, has the sixth worst Human Development Index ranking among Brazil's 26 states.<sup>43</sup> Nearly 85% of Brazilians live in urban areas,<sup>44</sup> including an estimated 22% who live in urban slums (locally known as “favelas”).<sup>45</sup> Communities living in urban slums typically have inadequate access to clean water and sanitation and other infrastructure conditions, which provide arboviruses, such as Zika, the ability to thrive.<sup>46</sup>

Rigid gender norms are deeply embedded in Brazilian culture and intersect with other forms of social vulnerability.<sup>47</sup> Although there has been progress in recent decades, there are still significant gender gaps in relation to employment, income, political representation, and family responsibilities.<sup>48</sup> Moreover, young, low-income, and other marginalized women have an unmet need for contraception despite supposed free access through the public health system. Poorly funded clinics and schools where sexual education is not provided make it hard for women to access quality information related to their sexual and reproductive health. As a result, as many as 20% of sexually active adolescent women in Brazil are not using birth control and approximately 55% of all pregnancies are unplanned.<sup>49</sup>

Brazil also has robust constitutional protections for children,<sup>50</sup> and for people with disabilities, which includes the right to special education,<sup>51</sup> proper public accommodations, and accessible transportation.<sup>52</sup> Brazil's Constitution also guarantees the payment of a monthly minimum wage to people with disabilities,<sup>53</sup> known as the *Benefício de Prestação Continuada* (BPC) or Continuous Cash Benefit, which is provided to those who prove a monthly family income lower than 25% of the minimum wage.<sup>54</sup> Moreover, Brazil has ratified

and incorporated the Convention on the Rights of People with Disabilities into law.<sup>55</sup> These public benefits and legal protections are crucial to a response to the Zika epidemic given the significant support needed by families with children born with Zika-related health complications.

Although enshrined in law, these principles frequently have little to no effect on the everyday lives of Brazilians. For example, despite constitutional protections relating to gender equality and health, Brazilian law severely restricts access to abortion. Enacted in 1940, the penal code prohibits abortion and establishes criminal penalties for women who consent to or induce abortion as well as for any third party who performs the procedure.<sup>56</sup> The penal code however, provides exemptions for cases when a woman's life is at risk or the pregnancy is the result of rape. In 2012, the Brazilian Supreme Court held that pregnancies resulting in anencephaly, a congenital condition in which all the major parts of the brain are missing, also constituted an exception under the penal code.<sup>57</sup> Even with these strict restrictions, one in five Brazilian women has terminated at least one pregnancy in their lifetime.<sup>58</sup> However, the majority of these abortions occur in a clandestine manner, often involving serious risks for women, especially the most marginalized.<sup>59</sup>

Religion also plays a key factor in Brazilian culture. Sixty-five percent of the population identifies as Catholic, 22% identifies as Protestant, and Pentecostal and other evangelical denominations are increasing.<sup>60</sup> Consequently, religion not only influences gender norms at the individual and family level, but has also negatively impacts government policies relating to gender equality and reproductive rights.<sup>61</sup> In the last 15 years, conservative movements such as the *Frente Parlamentar Evangélica* have aimed to bar the advancement of reproductive rights<sup>62</sup> and enact legislation to eliminate legal exceptions for abortion, increase criminal penalties for clandestine abortions, and prohibit the distribution of emergency contraception.<sup>63</sup>

Brazil's political economy could help explain why a disconnect exists between laws and policies and the experiences of women accessing sexual and reproductive health care. The Public Unified Health System (*Sistema Único de Saúde*, SUS) in Brazil is funded and managed jointly by all levels of the Brazilian government,<sup>64</sup> and 190 million people rely exclusively on its services.<sup>65</sup> However, the SUS contracts out the majority of its secondary care<sup>66</sup> to private companies, and many Brazilians who rely on the SUS encounter inadequate supplies and care.<sup>67</sup> In addition to long wait times for emergency services, patients also encounter infrastructure problems, outdated and malfunctioning equipment, and a lack of doctors and medicine, especially in rural areas.<sup>68</sup> This means that many Brazilians struggle to access specialized care, such as obstetrics or gynecological care.

The Brazilian government recently supported a constitutional amendment to freeze public expenditures on health and education for the next twenty years, a move that will place more financial responsibility on already overburdened municipalities. The United Nations described the public expenditure cap as a “radical measure” that “will hit the poorest and most vulnerable Brazilians the hardest, will increase inequality levels in an already very unequal society, and definitively signal that social rights are a very low priority.”<sup>69</sup> The measure is likely to impact the same low-income Brazilians who have already been disproportionately affected by both Zika and CZS, and will put additional strain on the public services that have been unable to meet the basic needs of people in regions affected by the virus.

## Testing and Surveillance

As of November 2017, the Pan American Health Organization estimated that there have been 231,725 suspected cases and 137,288 confirmed cases of the Zika virus in Brazil with an incidence rate of 176.10.<sup>70</sup> By October 2015, 56,318 suspected cases were reported in the state of Bahia alone, which is where the fieldwork for this report was conducted.<sup>71</sup> Not only has Bahia been one of the states most affected by the



epidemic, it is also where Zika was first isolated in Brazil by Dr. Gubio Soares Campos, a virologist at the Universidad Federal de Bahia, in April 2015.<sup>72</sup>

Despite Brazil's history with arboviruses,<sup>73</sup> an official with the state of Bahia's health secretariat said that the country was "unprepared" for the arrival of the disease.<sup>74</sup> An official with the state's office of epidemiology similarly noted that the state had "hardly been able to recover from one [outbreak] before another emerged," describing how in a short period of time the region had to shift from addressing a dengue outbreak through mid-2014 to investigating a chikungunya outbreak in early 2015 (originally thought to be another dengue outbreak) to responding to an outbreak of yet another arbovirus soon after which was identified as Zika.<sup>75</sup> What would eventually become one of the most defining characteristics of Zika, and what would set it apart from otherwise similar arboviruses, was the disease's impact on the reproductive health and decision-making of the population.

A major shortcoming in the surveillance of Zika has been the data collection of exactly who has been infected with the virus and specifically how the epidemic has affected existing social and economic inequalities. The official form used to notify and report new cases of Zika included questions regarding a person's age and race or ethnicity, but none with respect to a person's education or economic status; furthermore, the field for race and ethnicity was often left blank by health care professionals completing the forms.<sup>76</sup> This omission certainly may play a role in masking disparities within the epidemic. While a racial imbalance is strongly suspected, the government lacks consistently collected and reported data, making it difficult to study the connection between race and Zika.

As for surveillance of babies with Congenital Zika Syndrome, several interviewees emphasized the need for ongoing outreach and monitoring to identify those cases that were discarded because they did not fit criteria (i.e. they did not have microcephaly or a particular head circumference at birth) early on and/or because they had only presented symptoms of the syndrome months after birth.<sup>77</sup> Researchers from the organization ANIS, who carried out interviews with families of "discarded" cases in Alagoas, a neighboring state in northeast Brazil, found that a number of the babies now had visible abnormalities indicative of a possible Zika infection.<sup>78</sup> A technical analyst for social policies and the general coordinator for the Women's Health Program from the Ministry of Health explained, "We have emphasized for states and municipalities to reach out to these [discarded cases of] children and to strengthen their pediatric activities. It is in pediatrics that we will be able to identify whether a child who did not fit the earlier criteria of microcephaly is now presenting some other kind of difficulty [or] alteration of the nervous system."<sup>79</sup> However, she noted that as with many Ministry of Health guidelines, there were problems in the dissemination of information meaning that many policies and guidelines did not actually reach municipalities, or reached them much later than expected.

Obtaining a Zika diagnosis was identified as one of the main barriers during the outbreak, which had a direct correlation with women's reproductive health because it made it difficult for women to make informed decisions regarding their reproductive choices. A technical analyst from the Ministry of Health observed, for example, that some health professionals still have difficulties clinically differentiating between the symptoms of Zika and other arboviruses.<sup>80</sup> Indeed, women we spoke with in the Calafate community in Salvador described how, instead of providing a specific diagnosis, health professionals would often just tell them they had a virus. Moreover, although the government made efforts to incorporate Zika-related care into prenatal care and screenings, the sub secretary for health in Bahia noted that women who started prenatal care later in their pregnancies, and/or already faced financial or geographic barriers in accessing care, also faced barriers in getting timely information and screenings for Zika infections and related complications.<sup>81</sup>



Another challenge in testing has been ensuring the availability of timely and accurate tests so women do not have to wait several weeks for results and can make informed decisions about their reproductive health in a timely manner. The accuracy of tests is also critical as it would allow patients to make decisions with more certainty rather than relying on a doctor's clinical diagnosis that could easily be mistaken for another arbovirus. A researcher from Fiocruz, a scientific institution for research and development in biological sciences located in Rio de Janeiro, noted that the best test available was the real-time reverse transcription polymerase chain reaction (qRT-PCR),<sup>82</sup> which can be performed on a blood or urine sample.<sup>83</sup> However, the researcher also shared that the qRT-PCR test has not been readily available in Brazil because the country lacks the health care infrastructure necessary to administer it.

In 2016, the Bahia Health Department and the Brazilian Health Surveillance Agency (ANVISA) designed a new rapid test for Zika to quickly provide individuals with their test results.<sup>84</sup> This test was especially useful for people who had received an ultrasound showing fetal abnormalities, had clinical or laboratory indications of a Zika infection, or had come in contact with the bodily fluids of someone suspected of having Zika. As of the date of this publication, the rapid test is still being rolled out in several Brazilian states.<sup>85</sup> A state health official reported that in Bahia, health care professionals are currently being trained on how to administer the test, which will first be prioritized for use among pregnant women with the hope of making the service available to everyone later.<sup>86</sup>

Even women with partners diagnosed with Zika often lacked comprehensive information pertaining to the risks associated with being intimate with someone infected by Zika and options available to keep themselves safe. Several doctors noted that because there is still so much that is unknown about the virus, it is impossible to truly give patients all the information they would need to make informed decisions about whether or not to pursue a pregnancy.<sup>87</sup> Because research is still ongoing, it is impossible to tell women what the exact risks



might be for giving birth after being diagnosed with Zika.<sup>88</sup> Doctors also do not know how long it will take for the risks to a pregnancy to abate following a Zika infection, and thus are unable to advise women how long they must wait to safely conceive after having been diagnosed.<sup>89</sup>

## The Right to Access Accurate and Comprehensive Information

The right to accurate and comprehensive information includes seeking, receiving, and imparting information and education on reproductive health.<sup>90</sup> In order for women to be able to make the best and most informed decisions about their reproductive lives, states must ensure that they have access to both comprehensive sexual and reproductive health services and adequate health information.<sup>91</sup> The disseminated information must be accurate, unbiased, and evidence-based so women can make informed decisions about things like pregnancy and parenting.<sup>92</sup>

Information must also be disseminated in a timely and inclusive manner.<sup>93</sup> This means that states must ensure that information reaches the poorest and most marginalized populations to dispel any rumors and misconceptions that may exist about Zika and its prenatal complications.<sup>94</sup> States must also work to ensure that women and their communities are aware of how Zika is transmitted as well as the preventative measures available to mitigate the spread of the virus.

## Zika Prevention

As part of the decentralization strategy after Brazil's federalist constitution was enacted in 1988, the federal government dismantled its national public health agency and progressively shifted mosquito control responsibilities to local governments. According to the subsecretary of health for the state of Bahia, this process “destroyed [Brazil’s] system of controlling the vector.”<sup>95</sup> The subsecretary also noted that the Zika crisis revived the federal government’s concern over vector control, albeit in a context lacking infrastructure. While the national vector control system during the Zika outbreak may have been a severely weakened version of what it was before 1988, it was certainly a matter of governmental fixation as captured by the government’s slogan of the major Zika public health campaign: “A mosquito is not stronger than a whole country.” Many interviewees, including community educators and reproductive rights experts, criticized what they saw as the government’s narrow focus on preventing the disease through vector control, or “the mosquito,” rather than the development of a human rights-based response that would take into account the impact the virus was having on women’s reproductive health care<sup>96</sup> as well as the social determinants and inequalities that exacerbated the effects of the virus.<sup>97</sup>

To address the inadequacies in public efforts to control the mosquito population, the government advised individuals to wear insect repellent, especially if they were pregnant.<sup>98</sup> The federal government had planned on distributing free insect repellent to at-risk individuals at least as far back as late 2015,<sup>99</sup> but the program took over a year to go into effect. As a result, shipments only made it to the states as of March 2017 when the high season for mosquito activity was ending.<sup>100</sup> While there is now some availability of free repellent, the population has very limited access to it. Women must be pregnant and registered for a low-income government program known as *Bolsa Familia* to even qualify for free repellent. This scheme excludes many low-income women who do not meet the program’s economic threshold. The program is intended for the “extremely poor,” those with a per capita income of BRL 70 (approximately USD 25) per month, and for the “poor,” those with a per capita income between BRL 70 and BRL 140 (approximately USD 42) per month.<sup>101</sup> The program also excludes women who are not yet pregnant, but may soon become pregnant and thus need to protect themselves from infection. Additionally, access to the free repellent program is not extended to women’s male sexual partners who could become infected and transmit the virus to them sexually. The process can also be unnecessarily cumbersome. In Salvador, for example, qualifying women must visit a government office on a specific date and time to receive their first supply and then must go to a government health center for each additional supply. Women are also limited to two bottles per month of their pregnancy, which is unlikely sufficient for recommended use according to a nurse who works with the Salvador health secretariat on such matters.<sup>102</sup>

For those who are not able to access the limited supply of free insect repellent, purchasing it is another option though with its own limitations. A peer educator with the nonprofit *Reprotai* noted that the price of insect repellent seemed to double as demand grew during the emergence of Zika, adding that “the market does not forgive.”<sup>103</sup> While the amount of insect repellent sold in the country had risen by one-third during the epidemic, the revenue had doubled, suggesting a rise in prices and not just in units sold.<sup>104</sup> Claudia Vasconcelos, a feminist activist, said that while insect repellent is generally expensive, even for a middle-class woman like herself, “What they specifically recommend for pregnant women to use is even *more* expensive products.” Despite recommendations, she added that, “In practice, you use what you have.”<sup>105</sup> For example, Vanessa—one of the women interviewed from Subúrbio Ferroviário—used homemade insect repellent that she and her husband made themselves. Although she knew it was not as effective as store-bought insect repellent, she could not afford the BRL 90 (approximately USD 30) that she said the insect repellent would cost her per week if she went to a local store.<sup>106</sup>

Public health experts that were interviewed for this report indicated that they felt that the government's messaging around individual methods of Zika prevention—such as wearing long clothes, using insect repellent, and not collecting standing water—did not match the realities of affected communities. One feminist activist, who was pregnant during the epidemic, said that people would tell her she was “crazy” for not wearing long clothes, but the summer heat in Bahia could be unbearable dressed in that manner.<sup>107</sup> Indeed, the average temperature in Salvador in the summer of 2016 was approximately 30-31 degrees Celsius (86 degrees Fahrenheit), with a high of 34 degrees Celsius (93 degrees Fahrenheit).<sup>108</sup> Regarding the instruction to not collect standing water, the activist noted that the critical question was, “If one's community does not have water five days a week; how does one not collect standing water?”<sup>109</sup> She also felt that the conversation around prevention all seemed to involve the responsibilities—and thus potential culpabilities—of women. In contrast, she said, “There was no debate about the responsibility of the state.” An analyst from the Ministry of Health, specifically from a department focused on women's health, expressed similar concerns: “The repellent in a way places the responsibility of prevention care on the woman—we [already] live in a society that blames the woman for everything...if during the pregnancy she is infected with Zika, we blame her too...but the more important activities are sanitation and infrastructure for the provision of potable water.”<sup>110</sup>

## State Prevention and Treatment Obligations

State parties have an obligation to take every measure required for the prevention, treatment, and control of epidemics.<sup>111</sup> The government of Brazil is mandated to establish “prevention and education programs for behavior-related health concerns,” particularly those that adversely impact an individual's sexual and reproductive health.<sup>112</sup> Mitigating the spread of sexually transmitted infections like Zika, which adversely affects the sexual and reproductive lives of both women and men, requires such behavior-related prevention health programming.

States are also required to put systems in place for urgent medical care in cases of epidemics or health hazards.<sup>113</sup> This could be achieved through national governmental efforts or collaboration between governments and private entities. Ultimately, the goal is to ensure epidemiological surveillance and data is used and improved, all relevant technologies are made available, and other strategies of disease control are implemented or enhanced.<sup>114</sup> This report has illustrated that there is a need for greater epidemiological surveillance of Zika, particularly in marginalized and remote communities. Additionally, given that there is currently no vaccine available to prevent the transmission of Zika, relying on other preventative strategies, such as the enhancement of vector control management, the use of insect repellent, and improvements to water and sanitation infrastructure, has become even more important.

In the context of Zika, this primarily takes the form of better access to virus testing, medical abortion pills, and ultrasounds. To ensure that these things are readily available, governments can remove barriers by changing medical protocols or facilitating the approval of new testing technologies.

## Family Planning and Contraception

The Brazil Constitution guarantees an individual's ability to conduct family planning without interference from the state, and assures that the government will assist in communicating all relevant information and resources.<sup>115</sup> The Family Planning Law of 1996 further, notes that “all methods and techniques of conception and contraception that are scientifically accepted and that do not endanger the life and health of the people will be offered, with the guarantee of freedom of choice.”<sup>116</sup> Specifically, the Ministry of Health has registered eight contraceptives available for free through the Public Unified Health System (*Sistema Único de Saúde*, SUS), including oral and injectable contraceptives, emergency contraception, condoms, and diaphragms.<sup>117</sup> Despite legal guarantees and policies for free public access to contraception, 55% of pregnancies in Brazil are unplanned,<sup>118</sup> demonstrating that in reality it remains a challenge for women to access contraception.

A national survey of contraception use in urban households found that only 32.7% of Brazilian women aged 15 to 49 were using oral (28.2%) or injectable (4.5%) contraception.<sup>119</sup> Rural use is only slightly behind urban use.<sup>120</sup> In northeast Brazil, where we conducted the fieldwork for this report, the vast majority of women who were using contraception were paying for it themselves,<sup>121</sup> a finding reflected in the interviews we conducted where all participants voiced their dissatisfaction with the limited availability of contraception offered by the public health system.

While many women chose to buy their contraception rather than obtain it for free from the SUS, 17% of women who were paying out of pocket had actually attempted to get contraceptives from the SUS first, but did not succeed, further underscoring the failure of the system.<sup>122</sup> Beatriz Galli, an expert on reproductive health with the nonprofit group Ipas, explained that the main problem with the health care system in Brazil was one of continuity.<sup>123</sup> While many methods of contraception are technically available, she said, “the problem is that one month the method is available, the next month it isn't,” leaving patients without a consistent source—something that is essential in the effective use of contraception. Additionally, she said women do not receive adequate counseling on what method of contraception is right for them, and women who receive emergency care after having a clandestine abortion are not referred to services to access contraception afterwards.

Although advised to avoid pregnancy, each interviewee noted significant barriers in accessing contraception. Only one interviewee said that it was easy to avoid pregnancy for women who wanted to, and four out of five interviewees said that the responsibility to avoid pregnancy fell disproportionately on women over their male partners. Gabriela, for example, became pregnant after her husband stopped purchasing her oral contraceptive; it was too complicated to get the contraception for free from the public health system, and she could not afford to buy it on her own without her husband's financial support. In fact, every interviewee mentioned problems with the public health system as a barrier for family planning and accessing contraception. Rather than providing a critical safety net for individuals in need of family planning, the public health system was described as understaffed and understocked. Interviewees also noted long waits and excessive bureaucratic red tape as additional barriers, unless, as Vanessa pointed out, you had a personal connection to help you navigate the system. Many interviewees found it simpler to buy their contraception from a pharmacy, at least when they had the funds to do so.

As of March 2017, when our interviews were completed—well past the peak of the epidemic but at a time when Zika remained a threat in areas such as Subúrbio Ferroviário—interviewees seemed uncertain about their future. Vanessa, who shared feeling pressure from her husband to have a child and ideally wanted



to become a mother herself, was very fearful of becoming pregnant while Zika was still a threat. The uncertainty of the times left her questioning whether she wanted to pursue parenthood after all. “Today,” she explained, “I do not feel as ready as I thought I would when I was younger.”<sup>124</sup>

Despite risks associated with having Zika while pregnant, research has shown no increase in contraception sales during the epidemic.<sup>125</sup> Since an increase in contraception sales during the epidemic wasn’t found and no concentrated effort was made to improve the distribution of current inventories, reason suggests that there was no significant increase in the use of contraception among people living in affected areas. The lack of any systematic government efforts to increase contraceptive knowledge and availability also helps explain why there was no such increase in use.

Access to information about contraception, beyond what was particularly relevant to the Zika epidemic, was noted as a problem in Brazil by several interviewees.<sup>126</sup> Regarding communication around contraception, a psychologist who researches abortion among Brazilian adolescents expressed that young people were not getting any information at home or at school, and instead turning to the internet and friends for answers.<sup>127</sup>

In regard to contraception, women also reported that they were not provided with adequate information regarding the sexual transmission of Zika and how condoms were the best prevention method for sexually active people. “When the sexual transmission of Zika was confirmed in April [2016], the focus of mass communication campaigns was primarily on vector control and repellent use, leaving condom use out of the conversation,” said a representative from the United Nations Populations Fund. “The narrowness of the messages and avoiding references to sexual transmission contributed to building up a false sense of security. Consider, for instance, the woman who is putting on repellent, but not using condoms and assumes she is protected against Zika.”<sup>128</sup> Although the Ministry of Health issued guidance in May 2016 for health care professionals to discuss sexual transmission and condom use in sexual and reproductive health care settings and prenatal consultations,<sup>129</sup> it is difficult to assess the extent to which this guidance was actually incorporated into practice at health centers.



# SYLVIA'S STORY

## PREGNANT IN THE PANIC OF ZIKA

Sylvia is a 33-year-old small business owner and university student living in the Subúrbio Ferroviário region of Salvador, Bahia. In 2016, she recounted, “I discovered that I was pregnant and it was at the exact moment when this whole Zika thing was here, and this outbreak of microcephaly.”<sup>130</sup>

*Image is not of Sylvia and is solely representational.*



Sylvia discovered she was pregnant one month into her pregnancy. She was not immediately sure whether she would continue with the pregnancy or not. Even though she did not think she had yet contracted Zika, she felt that the information she received—largely from the news—was incomplete and confusing since reports indicated that Zika had many symptoms in common with other viruses, including dengue.

Because she had not yet decided whether to continue with the pregnancy, and understood that Zika could pose serious risks to a fetus, Sylvia took what steps she could to prevent contracting the disease. She avoided standing water, even for her dog, and tried to wear long clothes. She also started using insect repellent heavily, though she noted that the price jumped due to an increase in demand and was unable to encounter any program distributing free repellent to those in need.<sup>131</sup>

Despite the precautions she was taking, Sylvia felt she did not have enough information on how to prevent contracting Zika. At the time of the interview, she did not know that Zika could be transmitted sexually, and said that she believed most Brazilians thought the virus could only be transmitted by a mosquito bite. While a community health agent visited her area once, they never provided any relevant information. Instead, she said the health worker, “put a [chemical product] in the drain, just one time...he put up a piece of paper that said absolutely nothing...signed something...and went away. He said absolutely nothing and left.”<sup>132</sup> During the epidemic, she went to a health care provider twice, but the visit included no mention of Zika or how she could protect herself, nor was she ever tested for the virus.

Amidst her continued confusion and unease regarding Zika, Sylvia decided to voluntarily end her pregnancy in its third month. At the time she said, “it was very scary,” noting that other pregnant women she knew were also paranoid about contracting Zika during their pregnancies and the ensuing complications that could follow. Additionally, Sylvia felt that it might not be the right time in her life to have a child. Between these two concerns, she decided it was best to wait to become a mother. “I preferred to interrupt [the pregnancy] until it all ended so to have no problems in the future,” she said referring to the epidemic.<sup>133</sup> She emphasized that women in Brazil face significant fear and stigma regarding abortion, and that society treats women as if they do not have the right to decide what is best for their bodies, and that in choosing to abort “they were doing something wrong.”<sup>134</sup>

Sylvia reported wishing it had been easier to voluntarily terminate her pregnancy, and that women generally had better access to reproductive health information and services. She noted, for example, that her doctor had given her incomplete information about the side effects of using the contraceptive pill and that although she thought the injection was perhaps a better option, it was more expensive. She also emphasized that although the government provides some methods of contraception for free, not all health centers were equipped to distribute them and women often had to deal with long waits to access hormonal methods in particular. She also explained that men still have some resistance to using condoms and that women may feel embarrassed obtaining them at health centers or even pharmacies.

In regard to the country’s response to Zika, Sylvia thought it was “absurd” for the government to merely advise people to avoid pregnancy without assisting them in actually doing so, or acknowledging their right to get pregnant if they so desired. “You have a right to say, “Look, I want to be a mother now, or I don’t want to be a mother now,” she said but that right is not recognized by the government. While Sylvia hopes to be a mother in the near future, she said she feels safer waiting for the virus to no longer be such a threat before trying to get pregnant again.



## The Right to the Highest Attainable Standard of Health

The right to health is a fundamental right that is indispensable for the enjoyment of other rights and is enshrined in many international human rights instruments.<sup>135</sup> Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity. The human right to health is recognized in numerous treaties. Article 25.1 of the Universal Declaration of Human Rights states: “Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing, medical care, and necessary social services.” The International Covenant on Economic, Social, and Cultural Rights provides the most comprehensive article on the right to health in international human rights law. In accordance with article 12.1 of the Covenant, state parties recognize “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”

The U.N. Committee on Economic, Social, and Cultural Rights developed the content of the right to the highest attainable standard of health in its General Comment No. 14,<sup>136</sup> explicitly stating that it included a right to reproductive health, defined as “the freedom to decide if, and when, to reproduce and the right to be informed, and to have access to safe, effective, affordable, and acceptable methods of family planning.”<sup>137</sup>

## Respect for Women's Decision-Making and Privacy

The U.N. Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) explicitly recognizes a woman's right to decision-making, which includes the right to determine the number, spacing, and timing of her children, and to have access to the contraceptive information and services necessary to exercise this right.<sup>138</sup> The right to privacy protects the right of all people to make decisions about their private lives, and decisions about whether and when to start a family falls within this protected definition of privacy.<sup>139</sup>

Safeguarding women's autonomy and decision-making regarding their sexual and reproductive lives should be central to national, global, and regional responses to Zika.<sup>140</sup> In order to do this effectively, states must be attuned to the social, economic, and political realities that women face each day when trying to exercise their sexual and reproductive rights.

## Contraception Access

Both the U.N. Committee on Economic, Social, and Cultural Rights and CEDAW explicitly recognize that the right to reproductive health must include the availability of contraceptive information and services.<sup>141</sup> For women seeking to delay or avoid pregnancy, states must ensure that they have affordable access to a full range of contraception options. Access to safe, effective, affordable, and acceptable family planning methods of your choice is integral to the freedom to decide, if and when, to reproduce.<sup>142</sup> Requirements of third-party consent for access to contraception must be removed as international human rights bodies have consistently considered such requirements contrary to women's rights.<sup>143</sup>



## Caregiving and Children with Disabilities

As is generally the case with Ministry of Health guidance, states had the autonomy to determine how they would handle prenatal care during the Zika epidemic. Some states, including Bahia,<sup>144</sup> Pernambuco, and São Paulo, decided early on that they would offer a second ultrasound to women with Zika (or other viruses with the risk of vertical transmission).<sup>145</sup> According to an interviewed nurse, the city of Salvador tried to offer three ultrasounds to pregnant women, but because the municipality's public health facilities had too little capacity, it had to contract a private clinic to offer additional appointments.<sup>146</sup> Therefore, not everyone in Salvador was able to access the three recommended ultrasounds during pregnancy.<sup>147</sup> That being said, Salvadorian women were likely in a far better position than women in other parts of Brazil. A researcher at Fiocruz noted that many rural hospitals in the interior of the country generally lacked adequate ultrasound equipment or maternity wards to properly serve their populations.<sup>148</sup> As a result, many pregnant women only discovered complications with their pregnancies after they had given birth, either because they had not had an ultrasound after complications had developed during their pregnancy or the ultrasound they had been given was inadequate.<sup>149</sup>

In addition to insufficient access to ultrasounds, another flaw in the response to the Zika epidemic was the lack of adequate funding and coordination between various levels of health services, which often had to rely on complex interactions between municipal, state, and federal entities. For example, Public Unified Health System (*Sistema Único de Saúde*) health centers at the municipal level had to coordinate with state hospitals to facilitate access to specialized care needed, but the coordination process—combined with capacity issues at each level—led to long wait times for women.<sup>150</sup> A lack of primary health care facilities outside of urban areas was also noted as a barrier for women seeking referrals to specialists, a type of secondary care that was recommended by the government.

For those who had babies born with Congenital Zika Syndrome and other Zika-related special needs, several interviewees reported that the public health system was not sufficiently prepared to provide them with the necessary support services. When children were administered tests, diagnoses, and therapies, they were rarely provided with any type of psychological or social services.<sup>151</sup> As a result, the first-line care children received did little to assist with the issue of social inclusion and left parents to search out additional services throughout a fragmented health care and social services system.<sup>152</sup> One interviewed woman said that families faced a dearth of information regarding social support for their babies with special needs, and that without that information improving a child and family's social inclusion was impossible.<sup>153</sup> She added that parents needed to better understand how to connect their children to psychological services and social support and that the health care system needed to recognize that many of the impacted families came from low socioeconomic backgrounds and did not have the time or means to investigate services themselves.

Social inclusion and access to psychosocial support remain salient concerns for families with children with disabilities, particularly given the fact that many of the families affected were already among the poorest. These are the same families that have yet to be able to return to work, spend hours traveling to take their children to doctor's appointments, and struggle to access the basic medicines and medical equipment to meet their children's needs. As documented in this research, the state has failed to ensure that women and their families are successfully able to raise children with disabilities in affirming, supportive, and healthy conditions.



# REPROTAI

Rede de Protagonistas em Ação de Itapagipe

A REPROTAI é uma rede de crianças, adolescentes e jovens da Península de Itapagipe, fundada em 09 de agosto de 2004 por adolescentes e jovens da Associação de Moradores do Conjunto Santa Luzia, Associação Livre dos Moradores de Mangueira, Grupo de União e Consciência Negra (GRUCON) e Comissão Articulação e Mobilização dos Moradores da Península Itapagipe (Rede GAMMPI).

A rede conta com grupos culturais e instituições sociais de bairros da Península de Itapagipe e dos adjacentes: Lomba Fazenda Grande do Retiro, São Castano, Susuarana e outros.

Ao longo desse período várias atividades fizeram a identidade da rede, tais como: formação política pedagógica, encontros crianças, adolescentes e jovens e ações culturais, como: Teatro Cultural, Festivais de Dança, Corredor da Poesia, Cinema Praça Auto de Natal.





# JOANA'S STORY

## STANDING UP FOR THOSE IMPACTED BY ZIKA

Joana is a 35-year-old woman living in Salvador, Bahia who was infected with Zika while pregnant. After giving birth to a child with microcephaly, and finding a lack of government or health system support for families such as hers, she co-founded a nonprofit group called *Abraço a Microcefalia* (Embrace Microcephaly). It is one of the few support organizations in Brazil specifically created for families affected by Congenital Zika Syndrome (CZS). The organization has grown rapidly, providing crucial support to a community deeply impacted by the Zika epidemic. As of November 2017, the organization had approximately 20 active volunteers and 180 registered families.

*Image is not of Joana and is solely representational.*

The first and second ultrasounds that Joana received showed some fetal abnormalities, but microcephaly was only confirmed toward the end of her pregnancy, as is usually the case. Joana gave birth in December 2015 and found that the diagnosis was correct—her daughter was born with microcephaly.

On her daughter's birth Joana said, "She was born and with that a world of doubts, [and] questions emerged."<sup>154</sup> The public was in a panic over the sudden emergence of so many cases of microcephaly, but no one knew exactly what to do—what tests should be run, what doctors should be sought out, and what parents should do to ensure their child's health and well-being.

"Everyone was in a chaos," Joana explained. "Some doctors even suggested the creation of groups [on how to raise children with microcephaly], because it is important that we share information."<sup>155</sup> She took the advice and began reaching out to other families who were affected by CZS. Not surprisingly, given the lack of quality public information available, she found that many parents were struggling even more than she was. "I was getting people who did not know anything," she recalled. "Because it was a surprising situation, no one was prepared for it."<sup>156</sup>

Joana's story demonstrates the success of using mobile technology to strengthen networks among families impacted by Zika. The emerging organization she created stayed connected via WhatsApp, a popular instant messaging tool used in Latin America that allows for group conversations. Soon, there were 80 mothers in the messaging group that would regularly offer each other support and suggestions as well as share questions regarding the unique challenges of raising a baby with microcephaly. By April 2016, the group decided to start meeting in person to offer each other further support and invited professionals to join and help address some of their questions. Despite the developing support network, Joana shared many of the challenges families faced in attending these meetings, such as the stigma they felt at even leaving the house or the added transportation costs that were distressing given that paying for necessities like diapers and milk was already a struggle. Being unable to provide the basics for their families made it hard for many to focus on seeking out the help and psychological support they needed.

Given her own experience, as well as those of members of her community support group, Joana reported that she believes the government should focus more of their attention on supporting families affected by disabilities as a result of the Zika epidemic. Solely telling women to avoid pregnancy, especially when their ability to do so may be hampered by limited education and access to contraception, isn't enough. Plus, there are women who may want to become mothers and need the resources to be able to do so safely. "Women," she said, "should not have to live in fear of becoming parents if that's what they desire." She also noted that Zika withstanding, many children are born with special needs that cannot be prevented, and those children need social support too.

"We believe that we will build a more egalitarian society through the work of our nonprofit, *Abraço a Microcefalia*," Joana said, and that through this, "people will have greater acceptance of their children. Our goal is to have spaces for inclusion in parks and to have spaces for inclusion in schools."<sup>157</sup> Through this inclusion, the rights of both parents and their children to health, family life, education, and social participation can be realized.

## The Rights of Children with Disabilities

Protecting the rights of children with disabilities must be at the forefront of every state's response to Zika. The rights of people with disabilities are protected under the Convention on the Rights of People with Disabilities (CRPD).<sup>158</sup> CRPD states that people with disabilities are entitled to the full and equal enjoyment of all human rights and fundamental freedoms.<sup>159</sup> States must ensure that all the necessary support mechanisms and appropriate modifications are available and in place so that children with disabilities—and their caretakers—can enjoy and exercise all of their guaranteed human rights on an equal basis with others.<sup>160</sup>

The U.N. Committee on the Rights of the Child (CRC) recognizes the need to provide “material support in the form of special allowances as well as consumable supplies and necessary equipment, such as special furniture and mobility devices, that are deemed necessary for the child with a disability to live a dignified, self-reliant lifestyle, and be fully included in the family and community.”<sup>161</sup> In accordance with CRC, “[s]upport services should also include different forms of respite care, such as care assistance in the home and day care facilities directly accessible at the community level. Such services enable parents to work, as well as relieve stress and maintain healthy family environments.”<sup>162</sup>

In addition, General Comment No. 5 of the U.N. Committee on Economic, Social, and Cultural Rights (ESCR) recommends that states ensure the provision of social security and adequate income support to people with disabilities and their caretakers.<sup>163</sup> ESCR has also recognized that “as far as possible, the support provided should also cover individuals (who are overwhelmingly female) who undertake the care of a person with disabilities.”<sup>164</sup>





## Abortion Access

Like Sylvia, one of the women interviewed for this report, some women will decide that the risks posed to pregnancy by a potential Zika infection are too serious to bring it to term. In a society like Brazil, where many pregnancies are unplanned, a public health emergency like Zika, which has direct consequences for pregnancies, will likely mean that a significant number of women will want to voluntarily end their pregnancies. Issued in 1940, the Penal Code of Brazil prohibited therapeutic abortions, that is an abortion induced when a woman's physical or mental health was at risk. However, the law allowed exceptions to save the life of the pregnant woman or if the pregnancy was the result of rape.<sup>165</sup>

In 2012, the Supreme Court decriminalized abortion for women carrying fetuses diagnosed with anencephaly.<sup>166</sup> However, this exception did not allow for an abortion associated with the physical or mental health risks of a Zika infection or pregnancy with complications from the virus. Brazil's abortion restrictions have thus made it extremely difficult for women to legally exercise their reproductive rights in the context of Zika.

Despite recent increases in public support for a woman's right to choose<sup>167</sup> and the fact that, legal or not, one in five Brazilian women will terminate at least one pregnancy in the course of their lifetime,<sup>168</sup> there have been no further measures to decriminalize abortion in the country since 2012. As one Brazilian demographer explained, “[I]n terms of reproductive rights, the big failure [in Brazil's Zika response] was not opening a legal exception for abortion as they did in Colombia, where women can access abortion if their health is at risk, including mental health. Because of the emergency aspect of the epidemic, we should have implemented these changes—they were discussed but not implemented.”<sup>169</sup>

In Brazil, judges have some power to authorize abortions outside the narrow list of existing exceptions.<sup>170</sup> However, not all judges will exercise their authority to issue exemptions,<sup>171</sup> and several interviewees confirmed that they were not aware of a judge issuing an exemption specifically for Zika-related health concerns.<sup>172</sup> Even if a woman were able to meet the narrow conditions to access a legal abortion—something that would only apply to a very small number of pregnant women affected by Zika—many other barriers exist. For instance, a woman must often navigate an unfamiliar court system that might not be culturally competent in addressing their needs. Plus, if a woman is granted permission to access a legal abortion, there are few hospitals authorized to perform the procedure.<sup>173</sup>

Finding a doctor that performs abortions is a real challenge because many doctors refuse to perform the procedure out of fear that they will become known as “abortionists” or get sued. Many also claim moral or religious objections to performing the procedure. These barriers could explain why a public defender in Pernambuco, one of the regions most affected by Zika, said that she has not heard of a single case brought forward by a woman trying to legally access an abortion as a result of Zika.<sup>174</sup> She explained that in light of the Zika epidemic, there has been the emergence of an “invisible demand” for abortions, which supports the argument that women's experiences during the outbreak have been silenced within the public sphere.<sup>175</sup>

Fortunately, a recent Brazilian Supreme Court decision represents an important step toward the decriminalization of abortion. In a December 2016 *habeas corpus* case involving the employees of a clandestine abortion clinic in Rio de Janeiro, the First Chamber of Brazil's highest court held that the criminalization of abortion in the first trimester was a violation of a woman's fundamental rights. Although the decision is not binding beyond that case, it provides powerful constitutional analysis in support of the right to abortion, and the tone of the judgment indicates that a shift in Brazil's abortion laws may be on the horizon.

On August 24, 2016, the Brazilian National Association of Public Defenders (ANADep), an association of public attorneys, in conjunction with Anis: Institute of Bioethics, delivered a petition to the Brazilian Supreme Court

arguing that women who have contracted Zika, and are in a state of great mental anguish, should have access to abortion services.<sup>176</sup> The petition was anchored in the principle that a woman's right to dignity, health care, and freedom from psychological torture are rights that are enshrined in Brazil's 1988 Constitution.<sup>177</sup> It also proposed that medical and psychological reports verify the mental suffering of pregnant women seeking abortions.<sup>178</sup> In regard to the petition, Joaquim Nato, then president of ANADEP said, "abortion is not the main goal of the petition, but it is impossible to talk about Zika without addressing abortion."<sup>179</sup> On March 7, 2017, another petition was filed by the Socialist and Freedom Party in collaboration with Anis: Institute of Bioethics. This petition challenged the criminalization of abortion on any grounds until the twelfth week of pregnancy.<sup>180</sup>

Without access to safe and legal abortion, many women seek services in a clandestine manner. Nearly half of women who have abortions in Brazil use medications, often without medical supervision. It comes as no surprise then that nearly half of women who have abortions are hospitalized to complete the termination due to complications.<sup>181</sup> The Ministry of Health reports that approximately one-third of the obstetric services performed by the public health system are post-abortion curettage.<sup>182</sup>

Misoprostol, which was originally invented for the treatment of peptic ulcers, is widely used to induce abortion. Because the drug is highly regulated in Brazil, and only available for use in obstetric hospital wards, women seeking a medical abortion are dependent on the clandestine market. Because misoprostol can be expensive, some women, particularly younger women, may opt for other unsafe means to induce abortion, including herbal teas or vaginal probes.<sup>183</sup> In Rio de Janeiro, the drug is mostly accessed through drug gangs—some of whom only sell the drug to men to prevent women from controlling their own pregnancies.<sup>184</sup>

The government's strict regulation of misoprostol has not succeeded in making it particularly difficult to obtain, but has greatly increased the risks for women who could otherwise obtain a safe and effective drug under medical supervision. It has also put the price of misoprostol out of range for many women, thus compounding social inequities for the most vulnerable. Reports have suggested prices approximately BRL 200 (USD 60) in the country's largest city of São Paulo<sup>185</sup> to BRL 550 (USD 165) in the southeastern city of Belo Horizonte.<sup>186</sup>

Researchers and advocates have noted that access to safe abortion services, tends to be a privilege of the wealthy who are able to pay out of pocket and travel if need be to secure the service.<sup>187</sup> Moreover, disparities in financial means and access to safer procedures are often correlated with race, as reflected in the higher incidence of unsafe abortions among women of color. A study in five Brazilian cities found that across all methods used to induce abortion, for every White woman who had to be hospitalized to finalize the procedure, three women of color were hospitalized.<sup>188</sup>

Although there is not substantial evidence about whether, and to what extent, Zika might have impacted the demand for abortion, or the profile of women who might have sought out abortion care due to the virus, there are some indications that the epidemic and its surrounding uncertainties may have compelled more women to consider and seek out abortions. For example, Women on Web, an online provider of abortion medication, reported a statistically significant increase in requests for the medical abortion pill after the public health alert about Zika was issued.<sup>189</sup>

Women who seek follow-up care after pursuing a clandestine abortion are often met with hostility and threats, despite clear guidance from the Ministry of Health that health care professionals have a duty to treat women in these situations with respect, dignity, and confidentiality.<sup>190</sup> In reality however, women are met with intentionally long waits, threats that the police will be called, and judgmental attitudes.<sup>191</sup> Reproductive rights experts reported that although it is against the Penal Code and Code of Medical Ethics for doctors to disclose a suspected abortion to the police, in practice doctors are not reprimanded for breaking confidentiality.<sup>192</sup>

## The Right to Abortion

Under international human rights law, women have the right to “the highest attainable standard of physical and mental health.”<sup>193</sup> The U.N. Committee on Economic, Social, and Cultural Rights recognizes that the right to health includes “the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference.”<sup>194</sup> Restricting women’s access to safe and legal abortion, especially for those whose physical and/or mental health is at risk, jeopardizes many of their internationally protected human rights. In fact, U.N. human rights bodies have recognized the negative consequences of restrictive abortion laws on women’s health<sup>195</sup> and have consistently raised concerns about the inaccessibility of safe abortion services.<sup>196</sup> As recognized by the Office of the U.N. High Commissioner for Human Rights: “[e]nsuring access to these services in accordance with human rights standards is part of state obligations to eliminate discrimination against women and to ensure women’s right to health as well as other fundamental human rights.”<sup>197</sup>





## Socioeconomic Inequality and Zika

Our researchers conducted interviews with five women of reproductive age in a low-income region of Salvador called Subúrbio Ferroviário, which is comprised of 22 densely populated neighborhoods that are home to approximately 500,000 people.<sup>198</sup> As with other low-income areas in Brazilian cities, Subúrbio Ferroviário has poor water and sanitation infrastructure, thus increasing breeding grounds for mosquitoes and the risk of Zika and other arboviruses. The secretariat of health in Salvador confirmed 38 cases of Congenital Zika Syndrome in Subúrbio Ferroviário at the time our interviews were conducted in March 2017—the highest case number among Salvador’s districts.

The five women we interviewed all reported having received information about Zika from different sources, including television, newspapers, awareness campaigns, and public health care professionals. Only one woman said that she had seen public health workers in the neighborhood sharing information directly, although she felt that the level of information they shared was insufficient; three women said they had never seen public health agents in Subúrbio Ferroviário. Additionally, at least one interviewee, a 26-year-old woman named Vanessa,<sup>199</sup> said she felt that the government had deliberately limited the information available on Zika. “In my view, they hide and wait to divulge when they see that the thing has already crossed the line,” she explained. “You have to talk. You have to communicate.”<sup>200</sup>

All but one of the women interviewed reported using insect repellent during the epidemic to prevent a Zika infection. Vanessa found that insect repellent in stores was too expensive to consistently purchase so she made her own. She and her husband have been using a homemade mixture for months. Two other interviewees mentioned the cost of repellent as being prohibitive, particularly after demand for the product rose by at least one-third. One interviewee reported spending more than BRL 90 (USD 27) a week on insect repellent due to the elevated prices in her neighborhood. At this rate, insect repellent would amount to 41% of a minimum wage worker’s total income.<sup>201</sup> At one local pharmacy, post-epidemic prices ranged from BRL 59 to BRL 413 (USD 4 to USD 18) for 100mL of insect repellent.<sup>202</sup> Two interviewees said that they had not heard of any program offering free insect repellent; two others noted that while free insect repellent was possibly available from government health centers, they did not know how to qualify for it. Thirty-four-year-old Gabriela,<sup>203</sup> who was pregnant during the Zika epidemic, said that she and a friend who was also pregnant worked out a system to ensure they would both always have insect repellent to protect themselves, even though neither could maintain a consistent supply: “When she did not have any more repellent, I would give it; when I did not, she would give me.”<sup>204</sup>



## The Right to an Adequate Standard of Living

States are mandated to recognize the right to an adequate standard of living for everyone.<sup>205</sup> This includes the right to adequate food, clothing, housing, and the continuous improvement of living conditions.<sup>206</sup> The right to adequate housing applies to everyone, and includes the right to legal security of tenure, the availability of services and facilities, affordability of housing, habitability, accessibility of housing, suitability of location, and cultural adequacy.<sup>207</sup> In the context of Zika, states are obligated to “give due priority to those social groups living in unfavorable conditions by giving them particular consideration.”<sup>208</sup>

## The Right to Water and Sanitation

Longstanding infrastructure problems have been found to have exacerbated the Zika outbreak in Latin America and the Caribbean.<sup>209</sup> This was particularly true in the poorest areas of the countries that were hit hardest by Zika. In 2015, the U.N. General Assembly adopted resolution 70/169, which recognized the human right to safe drinking water and sanitation. The United Nations called upon all member states “to ensure the progressive realization of the right to safe drinking water and sanitation for all in a non-discriminatory manner while eliminating inequalities in access, including for individuals belonging to groups at risk and to marginalized groups, on the grounds of race, gender, age, disability, ethnicity, culture, religion, and national or social origin or on any other grounds, with a view to progressively eliminate inequalities based on factors such as rural-urban disparities, residence in a slum, income levels, and other relevant considerations.”<sup>210</sup> Thus, states are required to ensure that the right to water and sanitation is enjoyed by their population, a guarantee that could effectively mitigate the spread of Zika and future outbreaks of the virus.<sup>211</sup>

# Conclusion

In May 2017, just after research for this report was completed, the Ministry of Health of Brazil announced an end to the public health emergency that had been declared at the onset of the Zika epidemic.<sup>212</sup> In making this announcement, the Ministry of Health noted that the end of the crisis did not signify an end to services or the need for individuals to remain cautious.<sup>213</sup> This sentiment was echoed by several public health experts and human rights advocates who suggested that little had been done to address the shortcomings in public service during the epidemic that allowed Zika to become such a major problem in the first place.<sup>214</sup> In addition to those who are still at risk of contracting Zika, the virus will continue to impact those who were infected earlier and may become pregnant. For children born with Congenital Zika Syndrome (CZS) and their families, the impact of the epidemic—and the need for state services and support—will continue throughout their lifetimes.

Our research indicated that there was a lack of clarity in government messaging regarding access to and the availability of emergency contraception, and that women often lacked information about the risks associated with Zika needed to make informed decisions. For example, women did not know that Zika could be transmitted sexually and doctors did not always provide accurate and unbiased information regarding potential related pregnancy complications. Also, while abortion is legal in Brazil in some cases, we found that women were not able to access abortion services when they needed them. For example, we found that health care professionals frequently deny care based on personal religious convictions, which is an improper use of their right to freedom of religion. In addition, women seeking follow-up care after obtaining a clandestine abortion were often met with hostility and threats despite clear guidance from the Ministry of Health mandating the contrary.<sup>215</sup>

Data from the Ministry of Health revealed that the majority of CSZ cases were concentrated in the northeast region of Brazil, particularly in Pernambuco, Bahia, Paraíba, and Maranhão. Yet in these affected areas, social inclusion and access to support mechanisms were some of the largest concerns of families with children with disabilities. These families were among the poorest, making the added responsibility of taking care of a child with special needs even more difficult. Lastly, we found that the lack of investment in water and sanitation infrastructure by the government contributed to the conditions that increased the proliferation of mosquitos, quickening the spread of Zika.

Despite an end to the public health emergency declaration, some aspects of the government's response, such as free distribution of insect repellent to low-income women, have only recently begun after many months of delays.<sup>216</sup> Other policy and program recommendations have yet to be made at all, and related cases brought by abortion rights advocates regarding these inequities remain pending in the courts.<sup>217</sup> Last, but not least, threats of widespread cuts to social programs jeopardize whatever safety net currently exists in Brazil.<sup>218</sup> Even so, attention has begun to shift away from Zika prevention efforts to the challenges that enabled the epidemic to have had such a deep and disparate effect. While these challenges are debated, women impacted by the virus living in the most affected areas continue to suffer, living the consequences of the virus for years to come without their experiences and reality being a priority for the government.

# Recommendations



## Government Recommendations

- Guarantee comprehensive sexuality education in schools that address gender norms and power dynamics in sexual relationships, including the shared responsibility of boys and men in reproductive health and preventing unplanned pregnancies.
- Ensure that public education campaigns provide accurate, complete, and easily comprehensible information about the transmission of the Zika virus, including sexual transmission and its consequences. This should also include information about an individual's fundamental rights and policies related to protecting against Zika and its effects, including the right to free contraception and social assistance programs.
- Provide access to free or affordable insect repellent to women of reproductive age, particularly during peak mosquito seasons and in areas with a high risk of Zika and other arboviral diseases.
- Remove criminal penalties for women who terminate pregnancies and for doctors who perform safe, voluntary abortions.
- Enact legislation that allows women to access safe and legal abortion services, particularly in cases to protect their health.
- Guarantee all families and children affected by Congenital Zika Syndrome (CZS), particularly low-income families, access to social assistance programs necessary for their children's development and families' livelihood; these programs include a monthly minimum salary available through the BPC cash transfer program; access to quality public day care and other assistance to ensure that female primary caregivers are able to enter the workforce if, and when, they choose to; continuous and free distribution of medication, glasses, orthoses, prostheses, and other necessary medical devices through the Public Unified Health System (Sistema Único de Saúde); and free, safe, and regularly available transportation to treatment and support services through the country's municipalities.
- Ensure the implementation of policies to proactively counter disability discrimination or stigmatization and guarantee the inclusion of children affected by CZS in the school system and other social spaces.
- Intensify efforts to eliminate mosquito-breeding sites and ensure long-lasting control of *Aedes aegypti*, including the investment in water and sanitation infrastructure for communities that have been most susceptible to the spread of Zika and other arboviruses.
- Reject bill amendments to the Brazil Constitution, such as PEC 55, which would exempt education and health public spending, a move that could increase inequality levels among the poorest sectors of society.



## Health Care System Recommendations

- Improve the ability of health care professionals to detect and diagnose Zika and consistently provide demographic data, including a person's race/ethnicity, for reported cases as a means of better documenting the social inequities of the epidemic.
- Ensure that surveillance systems to monitor Zika in rural and peri-urban areas are on par with those in urban areas.
- Guarantee that all individuals, particularly adolescent and young women, have access to accurate information (using existing routes of information sharing like the internet and peer groups) about the prevention of pregnancy and sexually transmitted infections, including the sexual transmission of Zika.
- Provide the non-judgmental provision of a wide range of contraceptive methods, including long-acting and reversible contraceptives and emergency contraception to prevent unwanted pregnancies.
- Ensure that all pregnant women are able to access prenatal care early in their pregnancies and receive Zika prevention counseling, including information about the sexual transmission of the virus; timely screenings and treatment for Zika and other congenital infections; and sufficient supplies of condoms and insect repellent for them and their partners.
- Facilitate early diagnosis of CZS by guaranteeing the provision of a second ultrasound to all pregnant women living in areas affected by the Zika virus.
- Provide access to psychosocial care for all pregnant women living in areas affected by Zika, particularly those who have been diagnosed with an infection during their pregnancy.
- Train health care professionals to properly diagnose and refer or provide care for infants with CZS.
- Conduct medical re-evaluations of all reported cases of CZS that were discarded for microcephaly during the early months of the epidemic, particularly in the northeastern states, to identify cases that may now fit the broader criteria.
- Ensure that all health care professionals are knowledgeable about the Ministry of Health's guidelines on abortion, including exemptions for authorizing a legal abortion in cases of rape, risk to a woman's life, or fetal anencephaly, and the ethical and legal duties they are bound to requiring them to protect the confidentiality of a patient and provide post-abortion care, including in cases of clandestine abortions.
- Ensure that women who wish to terminate a pregnancy receive accurate information about their legal options, including harm reduction where the procedure is not legally available.
- Ensure future research meets the highest ethical standards while also vocalizing the needs of women, children, and their families. Research should also be solution oriented and facilitate more comprehensive access to health care, information, and support services for women and children living with disabilities.





## Private Sector Recommendations

- Partner with governments, the health sector, and civil society to provide services to populations affected by Zika, including distributing insect repellent, making information that combats stereotypes available, and providing free or fairly priced treatments, medicines, vaccines, and comprehensive health care services.



## Civil Society Recommendations

- Support the advancement of human rights by recognizing the impact Zika has on a person's socioeconomic status, gender, and race.
- Support ongoing public information campaigns about Zika with an emphasis on mobilizing the community and educating individuals about their health-related rights and social assistance programs or policies available to them.
- Monitor the implementation of long-term policies and programs related to sexual and reproductive health and social assistance for families and caregivers of children with disabilities.
- Engage in interdisciplinary, qualitative, and quantitative research efforts on the impact of Zika to develop evidence-based recommendations and best practices for laws and policymakers.
- Foster research on the long-term impact of Zika, facilitate community-led dialogue and networks among women affected by the virus, and promote knowledge sharing, particularly in areas with low surveillance, detection, and prevention public health systems.
- Partner with other civil society organizations to share data and build coalitions with other ally movements, such as the disability rights movement, and other strategic partners, such as public health organizations and the private sector.

# Endnotes

- 1 These included formal interviews with five experts as well as informal discussions with three additional experts for the purpose of background information and snowball sampling. Interviewees included experts currently or formerly with the WHO, UNDP, OHCHR, and IACHR. Additionally, in completing the analysis herein, transcripts were reviewed from interviews with experts working for U.N. agencies and entities in the countries studied for this report, including UNFPA and UNICEF in Brazil, UNFPA and UNDP in Colombia, and UNFPA and UNICEF in Brazil.
- 2 See PAHO/WHO, *Zika Cases and Congenital Syndrome Associated with Zika Virus Reported by Countries and Territories in the Americas, 2015 – 2017: Cumulative Cases*, June 8, 2017.
- 3 Press Release, British Medical Journal, Journal of Family Planning and Reproductive Health Care, More Than 50% of Women are Avoiding Pregnancy Due to Zika in Brazil, Dec. 23, 2016.
- 4 Brazil Ministry of Health, *Zika Virus: Epidemiological Profile of Women*, Health Surveillance Secretariat Epidemiological Bull., at 1, Vol. 47, No. 37 (2016), available at [http://combataedes.saude.gov.br/images/pdf/Virus\\_Zika\\_perfil\\_epidemiologico\\_em\\_mulheres.pdf](http://combataedes.saude.gov.br/images/pdf/Virus_Zika_perfil_epidemiologico_em_mulheres.pdf).
- 5 "WHO Director-General Summarizes the Outcome of the Emergency Committee Regarding Clusters of Microcephaly and Guillain-Barre syndrome," WHO Media Centre, Feb 1, 2016; Donald G. Neil Jr., "How the Response to Zika Failed Millions," *New York Times*, Jan. 16, 2017; interview by authors with Joana (Mar. 2017).
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- 2017; interview with Debora Diniz, Co-founder and Researcher at Anis: Institute for Bioethics and Professor of Law at University of Brasilia, May 2017; interview with Tarcila Lopes, Public Defenders Union (DPU), Public Defender for the Health Group, Mar. 2017.
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