

UNHEARD VOICES

WOMEN'S EXPERIENCES WITH ZIKA

THE GLOBAL RESPONSE

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THE GLOBAL RESPONSE

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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 viruses 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) hypertonia 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, 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 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 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.

Global Gag Rule: A policy stipulating that non-U.S., non-governmental organizations receiving U.S. family planning funding cannot inform the public or educate their government on the need to make safe abortion available, provide legal abortion

services, or provide advice on where to get an abortion. First introduced in 1984 by U.S. President Ronald Reagan, and reinstated in 2017 by U.S. President Donald Trump, the policy allows for exceptions in cases of rape, incest, and life endangerment. It is also known as the “Mexico City Policy.”

Global Outbreak Alert and Response Network (GOARN): A collaboration of existing institutions and networks, constantly alert and ready to respond coordinated by the World Health Organization. The network pools human and technical resources for rapid identification, confirmation and response to outbreaks of international importance.

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), 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 (IACEDPD): A regional instrument committed to eliminating discrimination in all its forms and manifestations against persons with disabilities, which was adopted on June 7, 1999.

Inter-American Convention on the Prevention, Punishment, and Eradication of Violence against Women (IACPPVAW): 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 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 the member states of the World Health Organization.

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 U.N. 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 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 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 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 and international law.

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 for defining 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 lasts 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.







PUNTO DE
HIBRACION

Foreword

The goal of this report series is threefold: firstly, it presents and evaluates the diverse impacts that the Zika virus has had on the reproductive lives of women living in Colombia, Brazil, 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 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 it 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.¹ 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 as 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 rights to exercise informed and autonomous decision-making.



The Global Response to Zika

Zika is an arbovirus that typically presents with mild symptoms such as fever, headache, rash, and muscle or joint pain, typically lasting for two to seven days;² however, it can also be asymptomatic.³ As such, it can be difficult to distinguish these symptoms from other arbovirus infections, such as dengue, yellow fever and chikungunya, which can impede a Zika diagnosis.⁴

Zika was first identified in monkeys in Uganda in 1947, and later in humans in Uganda and the United Republic of Tanzania.⁵ Since the virus has been identified, outbreaks have been recorded in the Federated States of Micronesia⁶ and in four other groups of Pacific Islands.⁷ In February 2014, the first case of Zika in the Americas was confirmed on Easter Island, Chile.⁸ Just over a year later, Brazil notified the World Health Organization (WHO) of reports of an illness characterized by a skin rash occurring in the northeastern region of the country. Although Zika was suspected, no tests for the virus were initially conducted.⁹ By April 2015, tests were conducted confirming a positive Zika diagnosis. A week later, Brazil's national laboratory confirmed that Zika was circulating within the country, marking the first report of Zika being locally acquired in the Americas.¹⁰

Given the mounting evidence demonstrating a link between the Zika outbreak and clusters of microcephaly and other neurological disorders, government officials in Brazil, Colombia, Ecuador, El Salvador, Jamaica, and Puerto Rico began recommending that women living in these areas postpone pregnancy.¹¹ In response to these warnings, in February 2016, the WHO declared the Zika epidemic a Public Health Emergency of International Concern.¹²

In November 2016, as the number of Zika cases decreased, the WHO declared an end to the epidemic's international emergency status. In response, some public health experts worried that losing this emergency status would deprioritize state efforts to effectively and efficiently respond to the epidemic.¹³ However, 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."¹⁴ Unfortunately, despite the WHO's clarification, that was not how the message was interpreted by governments in Zika-affected countries. Although new cases continued being reported, by May 2017 the Brazilian and Colombian governments had declared the national public health emergency over.¹⁵

Evidence suggests that the WHO and 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.¹⁶ It has been detected in semen, blood, urine, amniotic fluids, and saliva as well as in bodily fluids found in the brain and spinal cord.¹⁷

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.¹⁸ Additionally, while microcephaly can be diagnosed during pregnancy with ultrasound in the second trimester or early in the third trimester,¹⁹ in most countries diagnostic testing tools remain inconsistently implemented.²⁰

Men are more likely to sexually transmit Zika than women.²¹ Although the period in which someone living with Zika can transmit the virus sexually is currently unknown, there is evidence to suggest that Zika stays longer in semen than any other bodily fluid. The virus has been detected in semen in as many as 188 days after the onset of symptoms.²² A Zika infection can be confirmed with a blood or urine test.²³ These same tests can also detect other viruses such as dengue or chikungunya.²⁴

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.²⁵ These complications can range from mild to severe, and can even be life threatening.²⁶ 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.²⁷

Although there have been incidences of Zika for decades, the virus remains relatively poorly understood. For instance, the time from Zika exposure to the presentation of symptoms (also known as the incubation period) is still not clear.²⁸ At the time of this publication, there was no specific medicine or vaccine available for Zika.²⁹ Although a vaccine is currently in development,³⁰ in the case of Brazil, which was the epicenter of the epidemic, the government has said it will likely take researchers between three to five years to produce one.³¹

The International Response to Zika

As of March 2017, over 80 countries and territories have reported local cases of Zika transmission. Of these affected countries, 13 have reported sexual transmission and 31 have reported microcephaly or other congenital complications suggestive of a Zika virus infection.³² After the World Health Organization's (WHO) global health emergency declaration, the international community mobilized to respond to the Zika epidemic, ranging from national ministries of health to the private sector. While the WHO lifted the Zika state of emergency in November 2016, it declared that it "remain[ed] a significant enduring public health challenge requiring intense action."³³

Several leading public health and human rights experts have criticized the global response to Zika for being discriminatory and racist, particularly against women of color and economically disadvantaged communities.³⁴ While some experts in developed countries praised the use of travel advisories to keep tourists and business travelers from venturing into areas where they might be infected.³⁵ Whereas female tourists from developed countries were advised not to travel, impoverished women of color living at the epicenter of the virus were badly served and inadequately informed about the size of the problem or the repercussions Zika could have on women's health.





COLOMBIA 🇨🇴

DANIELA'S STORY: PREGNANT AND IN THE DARK

Daniela, a 27-year-old woman living in the city of Barranquilla, was infected with Zika by sexual transmission from her husband who had recently visited a coastal region with a high prevalence of the virus. When he presented symptoms, he chose not to seek medical care because he had heard that clinicians were only giving patients over-the-counter remedies like acetaminophen, which he could purchase for himself from a drug store. A short time after his illness, Daniela also became sick with what appeared to be Zika, although she too did not seek out medical care.

Image is not of Daniela and is solely representational.

A month after she had begun to feel ill, Daniela learned that she was pregnant.

She had private insurance so she made an appointment to see a doctor within her network for her first prenatal care visit. At this point she was concerned for the health and well-being of her child given her suspicion that she had recently contracted Zika. At the appointment, her provider asked her if she had the Zika virus, and she stated that she believed she had contracted it through sexual transmission from her husband. Unfortunately, her provider never tested her to confirm her self-diagnosis—an omission her doctor later admitted was “an error” as Daniela should have been tested during that first visit. “When I started my prenatal care,”³⁶ she said, “they could have done tests on me to see if I had Zika. But they didn’t confirm if I had Zika or not,” said Daniela.³⁷

Based on the description of her and her husband’s symptoms, Daniela’s doctor believed that she had, in fact, been infected with Zika, and deemed her pregnancy to be high risk as a result. In the immediate weeks following, Daniela received enhanced testing and was sent for more detailed imaging of her fetus’s development. However, in a deviation from recommended practices by the Colombian government,³⁸ no one ever spoke to her about the potential risks posed to her pregnancy by Zika. Noting that her doctors never spoke to her about termination she said, “The doctors that I was seeing at that time didn’t even give me any options³⁹ nor did they draw blood.”⁴⁰ At home, she reported feeling disoriented after hearing on the news the potentially grave consequences for pregnant women infected with Zika. She told her obstetrician that she was experiencing a great deal of distress from the situation, but her doctor never offered her any information about the risks nor did he refer her to psychological services. Instead, all her providers merely said, “Your baby is okay,” leaving Daniela to deal with her anxiety and uncertainty alone.

“More than anything, my [medical] attention was physical,”⁴¹ Daniela explained, and never, “emotional, psychological, nor educational.” This left a significant gap in the care that she desired during her pregnancy and what she received. A Zika diagnosis, she said, “affects you psychologically and emotionally. It debilitates you mentally because you are concerned over something you can’t see or observe.”⁴² By failing to provide her with sufficient information and support during her pregnancy, her doctor exacerbated these problems rather than addressing them head on. In the end, her physician’s knowledge of her Zika diagnosis only meant that Daniela received some limited additional testing and a little more monitoring and reporting to the government—actions that helped in the collection of data, but nothing that ultimately helped Daniela.

Although her distress and anxiety persisted throughout the duration of her pregnancy, Daniela said that because she was never presented with proof of a malformation in her fetus, she never really considered the option of terminating her pregnancy, though the thought crossed her mind. All of her providers omitted any discussion regarding the risks involved in her pregnancy, her medical and legal options given those risks, or what additional steps she could take to come to a decision.

In the end, Daniela gave birth to a baby with no apparent complications from her supposed Zika infection or otherwise. However, a specialist never examined her baby and no ongoing tests have been provided despite the possibility of Zika-related complications developing as the infant ages. For example, research has found that babies born to mothers with Zika may develop problems with their eyesight long after having been deemed clear of Zika-related complications, and many experts believe children may experience other unknown complications as they age.⁴³

After giving birth, Daniela was not given any information on family planning, a critical service for all postpartum mothers, and something that was especially desired by Daniela due to her lingering concerns about what a Zika infection could mean for a future pregnancy. Her providers never offered her any advice following the birth of her child on how she might postpone an additional pregnancy should she still be concerned about Zika. Nonetheless, Daniela decided to focus on her first child and avoid becoming pregnant again soon. “It was a decision I made with my husband to wait for some time before having another baby.”

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World Health Organization (WHO) and the Pan American Health Organization (PAHO)

At the United Nations, the WHO led the global response strategy for the Zika epidemic, from detection and prevention to care and support for those affected.⁴⁴ Two weeks after declaring the Public Health Emergency of International Concern, the WHO launched a global strategic response framework and joint operations plan to guide the international response. “The strategy focused on mobilizing and coordinating partners to assist affected and at-risk countries” across the three core areas identified by the United Nations.⁴⁵ However, of all the 23 partners that were identified to work with the WHO to implement a response strategy, none of the partners were reproductive health experts or organizations.⁴⁶

To better coordinate efforts, the WHO established an “Emergency 4Ws Portal” on its website to act as a central point of reference for partners and show in real time who was doing what, where, and at what scale.⁴⁷ As of May 2016, the online portal had tracked more than 500 partner activities and associated budgets. The goal was to direct efforts where they were most needed, minimize duplications and deficits, and boost the cost-effectiveness of activities.⁴⁸

In conjunction with the WHO, PAHO worked closely to execute this response.⁴⁹ Together, they mobilized the Global Outbreak Alert and Response Network to assist ministries of health in strengthening the detection of Zika. By May 2016, the WHO had published 16 guidance documents that covered all aspects of the response.⁵⁰ Throughout the response to the Zika epidemic, the WHO acknowledged that the understanding of the virus was evolving in real time. This was apparent in the travel advisories issued by the U.S. Centers for Disease Control and Prevention (CDC) and the WHO. The CDC issued a travel warning advising pregnant women to consider postponing travel to areas with Zika outbreaks, and also advised women trying to get pregnant to first consult with a health care provider;⁵¹ similarly the WHO advised women who were pregnant to avoid Zika-affected areas.⁵² In response to these travel warnings, some criticized the WHO’s advisory, contending that its focus on politics and business, more than medical prevention, was the result of the potential economic impact such an advisory could have on tourism in Brazil at a time when the Olympics were about to take place.⁵³

Released in June 2016, an updated version of the WHO’s Zika strategic response plan included recommendations on how to mitigate the sexual transmission of Zika in addition to a more prominent vector management strategy.⁵⁴ More explicitly, the strategy advocated for “access to family planning, counseling, contraceptive services, including emergency contraception, and [...] safe abortion services (where legal), and post-abortion care.”⁵⁵ One of the WHO experts we interviewed stated that future research from the organization hoped to assess the availability of contraception and abortion-related care in several Zika-affected countries.⁵⁶ They further underscored the fact that although the global health emergency declaration had ended, “these research studies are going to continue, no matter what.”⁵⁷ Meanwhile, the WHO has since released interim guidance on pregnancy management in the context of Zika virus infections.⁵⁸

The WHO expert also praised the ethics statement issued by PAHO in May 2016, which came out strongly in favor of reproductive rights despite political sensitivities around issues such as abortion and contraception.⁵⁹ PAHO’s statement highlighted the importance of “women’s moral right to choose among all relevant reproductive options.” It also noted that “[p]roviding all available information in an honest and transparent manner is a crosscutting ethical duty of health care providers, ministries of health, and governments.”⁶⁰ The WHO interviewee said that this declaration was useful in promoting a response to the Zika virus that was centered around reproductive rights,⁶¹ and echoed issues raised by other interviewees that a human rights approach was missing by various international actors.⁶²



United Nations Population Fund (UNFPA)

As the world's leading international organization advocating on maternal and reproductive health, and the biggest public-sector supplier of family planning commodities, UNFPA has had a central role in the global response to Zika.⁶³

UNFPA former Executive Director, Dr. Babatunde Osotimehin, stated that the agency “will continue to lead efforts to promote widespread information about the virus and about voluntary family planning.”⁶⁴ During the Zika outbreak, UNFPA urged the international community to increase access to sexual and reproductive health in light of Zika with a special emphasis on family planning.⁶⁵ However, given the current global political climate in the United States, UNFPA has been the biggest target of budget cuts by the U.S. government, which claims that the organization's operations violate anti-abortion policy.⁶⁶

United Nations Development Programme (UNDP)

UNDP, the largest U.N. agency that works to eradicate poverty and reduce inequalities through the sustainable development of nations in more than 170 countries and territories, released a large study that assessed the socioeconomic and structural inequities that have exacerbated the Zika epidemic in Latin America.⁶⁷

The report assessed the long-term socioeconomic impact of Zika and recognized the direct and indirect costs of the epidemic on a larger scale, concluding that the outbreak will cost Latin American countries between \$7 to 18 billion.⁶⁸ According to UNDP, Zika disproportionately affected the poorest countries of the region, as well as the most economically vulnerable communities, with a special emphasis on poor women in peri-urban communities.

Organization of American States (OAS)

At the regional level, OAS Secretary General Luis Almagro underscored the need for a comprehensive approach to the Zika outbreak that considered a human rights perspective and included strategies to ensure affected families got the care they needed. He also said that the Inter-American Commission on Human Rights and U.N. agencies must coordinate efforts to create a coalition to tackle the Zika epidemic.⁶⁹ In light of this call, and a month after the WHO's global health emergency declaration, the Inter-American Commission on Human Rights (IACHR) joined the call of the Office of the United Nations High Commissioner for Human Rights (OHCHR), which stressed the importance of fully guaranteeing all women's sexual and reproductive rights for an effective response to the Zika public health crisis.⁷⁰ In October 2017, the IACHR held a thematic hearing on the human rights implications of Zika where civil society groups testified before the IACHR on the human rights violations in the countries most affected by Zika.⁷¹



Lack of Funding to Address the Zika Outbreak

Funding has been one of the most prominent issues that organizations have faced in being able to effectively respond to the Zika epidemic at the global level. Thus, to implement the global response framework developed by the World Health Organization (WHO), the organization requested USD 17.7 million in funding, but as of May 2016 had only received USD 2.3 million.⁷² As a result, in May 2016, former U.N. Secretary-General Ban Ki-moon established the U.N. Zika Response Multi-Partner Trust Fund, a multilateral fund to finance critical priorities in the response to the Zika outbreak.⁷³

In the United States, the Centers for Disease Control has also struggled to mobilize funding for the global response to Zika. In February 2016, the White House pushed to approve USD 1.9 billion in emergency financing to fight Zika. Unfortunately, the bill got caught in Congress amidst political divisions concerning abortion. After months of back and forth between Republicans and Democrats, USD 1.1 billion in funding got approved in May 2016—USD 800 million shy of what was initially requested.

The Global Gag Rule (also known as the “Mexico City Policy”) is a U.S. policy stipulating that non-U.S., non-governmental organizations receiving U.S. family planning funding cannot inform the public or educate their governments on the need to make safe abortion available, provide legal abortion services, or provide advice on where to get an abortion.⁷⁴ The Global Gag Rule has been projected to contribute to at least 6.5 million unintended pregnancies, 2.1 million unsafe abortions, and 21,700 maternal deaths as well as half of the introductions of new, effective contraceptive methods.⁷⁵ However, the financial limitations for responding to the Zika crisis and future epidemics were aggravated in January 2017 when the Trump administration reinstated the Global Gag Rule.⁷⁶

The funding restrictions imposed by the Global Gag Rule could dramatically affect the work of reproductive health advocates and providers across the world.⁷⁷ In 2003, the Global Gag Rule Impact Project reported that the policy has caused shortages in USAID supplied contraceptives in nearly 16 countries in Africa, Asia, and the Middle East. Just in Kenya alone, the policy and loss of USAID funding resulted in two of the leading family planning NGOs (Family Planning Association of Kenya and Marie Stopes International Kenya) closing five of their clinics and cutting their staff by as much as 30 percent.⁷⁸

The United States has been one of the largest funders of the United Nations Population Fund, behind only the United Kingdom and Sweden among country donors in 2015.⁷⁹ Pro-reproductive health groups have said that lost funding from the Global Gag Rule could have prevented 2 million unintended pregnancies around the globe, a salient thought to consider in the aftermath of the Zika outbreak across the Americas.⁸⁰



Despite these funding cuts, there have been positive strides made in other parts of the world. In Europe, for instance, there was a significant amount of collaborative research done to combat Zika. The European Union invested EUR 45 million in research efforts, which will be divided among three research consortia: ZikaPLAN, ZikaAction, and ZikAlliance.⁸¹ These consortia collaborate with response efforts located in Latin America and the Caribbean.⁸² An additional EUR 5 million in Horizon 2020 funding will support the ZIKAVAX consortium that aims to develop a safe and effective vaccine against the infection.⁸³

Several nations have also started to raise funds to replace a funding shortfall of USD 600 million over the next four years denied to organizations by the U.S. Global Gag Rule.⁸⁴ Led by the Dutch Minister of Foreign Trade and International Development, Lilianne Ploumen, fifty governments convened at the She Decides conference in Brussels to bring together world leaders to step up as a matter of urgency to the Global Gag Rule and make up missing funds.⁸⁵ On January 21, 2017, the Dutch Minister put EUR 10 million on the table, and in an announcement by the French Secretary of State in charge of gender equality, Marlene Schiappa, at the 62nd session of the Commission on the Status of Women in New York, pledged an additional EUR 10 million to She Decides conference from the government of France.⁸⁶

The Response from the Private Sector

The private sector has also taken big steps to help fund the Zika response by announcing large donations to several organizations. For example, the Bill and Melinda Gates Foundation committed USD 20 million to fight the budget cuts reproductive health organizations were facing; there was also a USD 50 million donation from an anonymous donor, and a USD 10 million personal donation from Sir Christopher Hohn. To date, She Decides is now being led by 36 world leaders, ranging from ministers to youth leaders, unlocking resources of EUR 390 million thus far.⁸⁷

Given today's political climate that has left foreign aid programming in limbo, public-private partnerships have been identified as an important alternative funding source to diversify financial support needed for the Zika response. For example, SC Johnson, one of the world's largest producers of insect repellent, has made donations to at-risk regions in the United States⁸⁸ as well as to the Centers for Disease Control Foundation⁸⁹ and the International Federation of Red Cross and Red Crescent Societies.⁹⁰ SC Johnson has also worked with domestic nonprofits in affected countries, such as the Children's Health Association in Rio de Janeiro, Brazil.⁹¹ While the company noted in an interview with the researchers of this report that they have been "happy to provide donations and work through the logistics of how best to transport the product" the real success of the response effort, including questions of social inequities and justice, must ultimately fall on their partner service provider organizations and/or governments on the ground.⁹² Although this could be interpreted as a call for a more synergetic relationship, it equally served as a reminder that in order for the private sector to successfully engage in response efforts, it is crucial that civil society and social systems be strengthened in the regions they are targeting with their donations.



BRAZIL 

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.”⁹³

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.⁹⁴

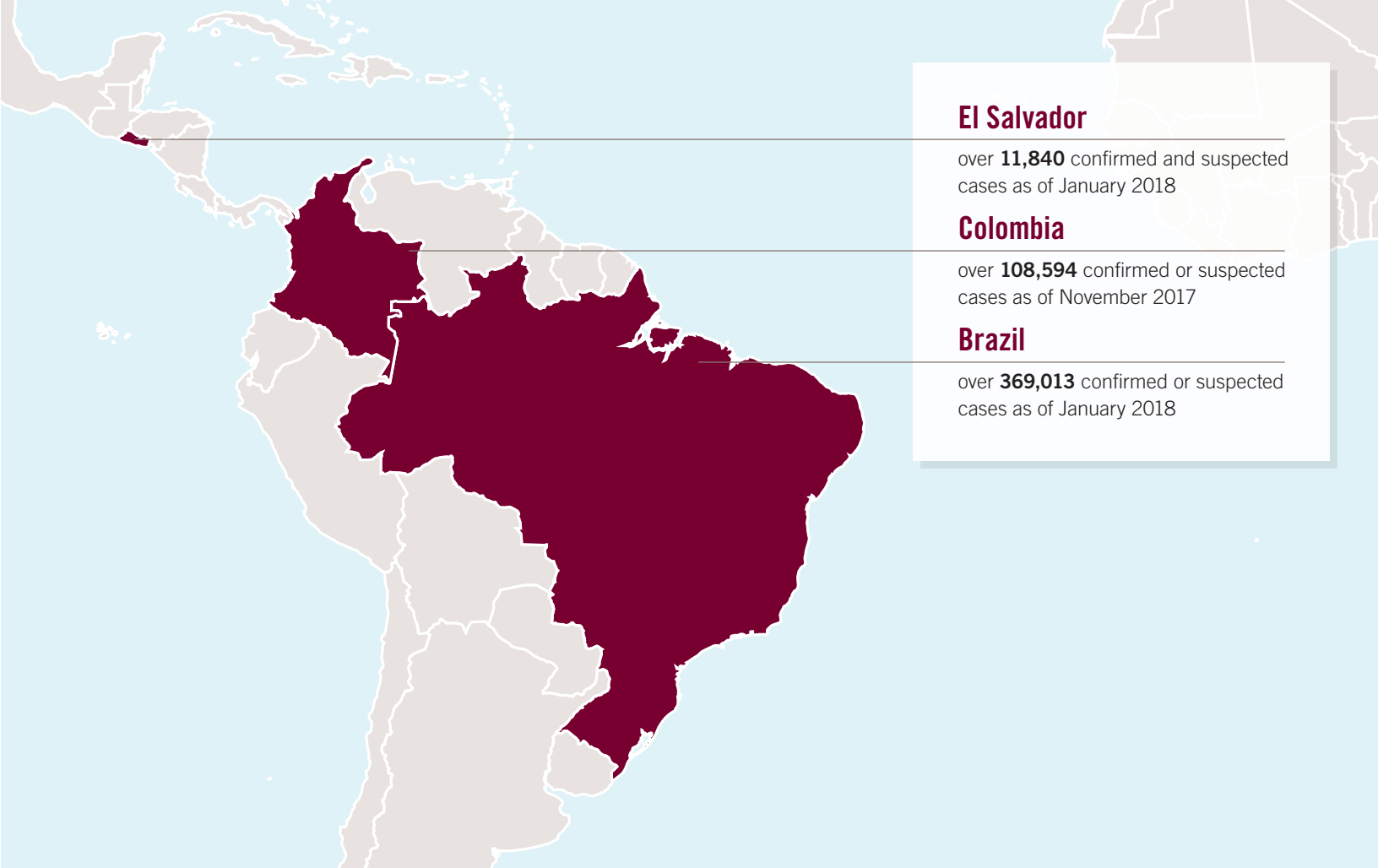
Despite the precautions she was taking, Sylvia felt she did not have enough information on how to prevent contracting Zika. At the time of the interview, she did not know that Zika could be transmitted sexually, and said that she believed most Brazilians thought the virus could only be transmitted by 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.”⁹⁵ 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.⁹⁶ 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.”⁹⁷

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.





Case Studies: Brazil, Colombia, and El Salvador

Latin American and the Caribbean government's response to the Zika epidemic showed a lack of consideration for the lived experience and rights of women with Zika and their children born with disabilities. Throughout the crisis, the governments of Brazil, Colombia, and El Salvador consistently advised women to delay pregnancy and worked to devise vector control strategies to mitigate the spread of Zika. However, this approach did not adequately integrate a human rights-based approach and did little to ameliorate complications resulting from the epidemic.

Several public health experts interviewed for this report series criticized the prioritization of vector control strategies as a means of managing the spread of Zika. This prioritization suppressed other preventative strategies, such as the provision of 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 regions in Latin American and the Caribbean with reported cases of Zika, impoverished women living in infected areas in these countries were simply instructed to avoid getting pregnant.⁹⁸ 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 were frequently met with violence, stigma, or criminalization when seeking out reproductive health services, if they were available at all.⁹⁹



Brazil 🇧🇷

In April 2015, the first signs of Zika hit Brazil. As of January 2018, over 369,013 suspected and confirmed cases have been reported,¹⁰⁰ including 1,845 confirmed cases of Congenital Zika Syndrome (CZS) in babies.¹⁰¹ The majority of these reported cases occurred among women, particularly women of reproductive age.¹⁰²

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

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. Research also indicated that the declaration of Zika as a public health emergency led to an increase in the number of abortion requests in Brazil received by Women on Web, an organization that provides information on medical abortions.¹⁰³

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.¹⁰⁴ 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.¹⁰⁵ In addition, we found that doctors were also struggling to provide patients with accurate and religiously unbiased information regarding Zika-related pregnancy complications.¹⁰⁶

In regard to safe 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 conscientious objection laws. 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.¹⁰⁷

Some of the largest concerns of families with children born with Zika-related disabilities were social inclusion and access to support mechanisms. 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. In the case of Brazil, we found that women were the main caregivers of children. We documented the stories of women who had to quit their jobs and were no longer able to go work or study because of their caretaking duties. Women also often reported needed 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.



Colombia

With over 108,594 confirmed or suspected cases of Zika as of November 2017, Colombia is second only to Brazil in terms of the number of reported cases.¹⁰⁸

During on-site visits in the north of Colombia, our research indicated that language affirming the sexual and reproductive rights of women was largely absent from Zika-related public health campaigns or government responses. Like in Brazil, cost was often flagged as a barrier in accessing contraception and lengthy travel distances to clinics were also highlighted as making access to sexual and reproductive health services a challenge. Numerous women we interviewed also indicated that there was ambiguity in government messaging, and that women were often unsure, or even unaware, of the risks associated with Zika.¹⁰⁹ In addition, we found that doctors were also struggling to give patients the required and religiously unbiased information that they needed as their understanding of Zika was, and remains, relatively limited.

In Colombia, there were also stark differences noted in contraception access between urban and rural areas. In rural areas, women faced many geographic barriers (e.g. long trips to quality clinics or clinics where they could access contraception anonymously) and variations in the quality of access (e.g. incomplete or inaccurate information or lack of access to long-term forms of contraception).¹¹⁰

In our interviews, we asked four at-risk women if they faced barriers in accessing contraception. Three said yes; one said she was unable to find injectable contraception from a public-sector provider; another said that the cost in general made access a challenge; and a third said that only some types were affordable with insurance whereas other types required large out-of-pocket costs. Several said they had used contraception in the past—for family planning, safer sex, or both—but had not used them to specifically avoid pregnancy during the Zika crisis.

Abortion is legal in Colombia under three circumstances: (1) when the continuation of a pregnancy poses a physical or mental risk to the life or health of the woman, (2) when the fetus has a fatal malformation making life unviable outside of the uterus, or (3) when the pregnancy is the result of sexual assault, incest, or otherwise without consent.¹¹¹ Despite the legality, it is not always easy for women to access abortion services. Health care professionals, insurance plans, and medical settings frequently deny care based on their own personal religious convictions in what is an improper use of conscientious objection laws. Doctors we interviewed in Colombia, both of whom provided abortions in public and private clinics, also cited a lack of adequate information regarding abortion as a leading barrier to accessing care.



El Salvador

With over 11,840 confirmed and suspected cases of Zika as of January 2018 in El Salvador—the highest incidences reported in the departments of Chalatenango, Cuscatlán, and Cabañas—has the third highest incidence of Zika in Central America.¹¹²

From the first documented cases of Zika in late 2015 to early 2017, health authorities reported a total of 371 pregnant women suspected of having the Zika in El Salvador.¹¹³ While the Pan American Health Organization only reported four cases of Congenital Zika Syndrome in the country,¹¹⁴ the United Nation's Children Fund reported that a comparison of pre- and post-epidemic rates of microcephaly indicated that the number of Zika-related cases may actually be much higher.¹¹⁵

In El Salvador, the long-term impact of the virus remains poorly understood, and the experiences of women and their families have been largely ignored by the government and health authorities. In a country that has one of the highest rates of teenage pregnancy in Latin America (one-third of all Salvadoran babies are born to girls and women under the age of 19),¹¹⁶ advising women to avoid pregnancy was not a realistic strategy.

Our research found that women in El Salvador encountered serious barriers in exercising their sexual and reproductive rights and that crosscutting gender norms and inequities placed grave limitations on options for low-income women living in remote and rural areas. In a country where abortion remains illegal in all circumstances, even when women have been victims of rape or their health and life is at risk, our research indicated that language affirming the sexual and reproductive rights of women was completely absent from any Zika-related public health campaigns or responses in El Salvador.

The ability to control family planning was a critical challenge in responding to the threats posed by Zika. In El Salvador, the highly conservative and religious culture has hindered access to contraception, making family planning all the more difficult. During on-site visits to pharmacies in the city of San Salvador, our research found that health care professionals often denied patients contraception based on their own religious beliefs and women were apprehensive in seeking out contraception given the negative stereotypes associated with its use.

Under Salvadoran law, parental consent may be required for medical procedures for women under 18, which also proved to hinder access to contraception among adolescents. Furthermore, during our research we found that health care professionals have interpreted the phrase “promoting or facilitating the corruption of a person under the age of eighteen” in Article 167 of the Penal Code to mean that they



could be criminalized for prescribing contraception to women under 18.¹¹⁷ Although the U.N. Committee on the Rights of the Child and the World Health Organization have said that parental consent is not needed for adolescents to access contraceptive information and services, the ambiguity in the interpretation and application of these kinds of laws has broadened health care professionals' discretion in the provision of contraception.¹¹⁸ We found that the government must strongly consider the impact of this ambiguity on women's family planning ability as demonstrated most notably by the rate of pregnancy among adolescent mothers at risk of Zika-related complications.

In relation, El Salvador's has one of the world's most restrictive abortion laws. Not only is abortion illegal in all cases—even to save a woman's life—in practice it can also carry a prison sentence of up to 50 years.¹¹⁹ Furthermore, it is a blanket offence in El Salvador for public employees or officials of any public authority, including hospitals and clinics, to fail to report crimes in complete disregard of patient's confidentiality, which has been interpreted to include abortion.¹²⁰ As a result, many women who suffer serious, unprovoked complications in pregnancy, such as a miscarriage, opt not to seek health care assistance due to fears that they will be prosecuted and imprisoned. In the event that women do seek medical attention, they face the risk of being unjustly reported and prosecuted without adequate legal advice or representation.¹²¹

In November 2017, the U.N. High Commissioner for Human Rights, Prince Zeid bin Ra'ad Al Hussein, asked for a moratorium on the application of Article 133 of the Salvadoran Penal Code with the aim of ensuring compliance with due process and fair trial standards and the release of women unjustly imprisoned for having an abortion. In his statement, the High Commissioner called on the president and the legislative assembly to comply with its international human rights obligations and legalize abortion.¹²² Although two pending bills might change the restrictive abortion ban in El Salvador, to date the government has not advanced any efforts to implement these recommendations and women suffering from abortion related offenses continue to be jailed.

While these women's convictions occurred before the start of the Zika epidemic, the crisis has shined even more light on the injustice women face when they are denied any choice over their reproductive health and family planning options. The lingering presence of Zika, which is now endemic in the region, could continue to impact the health of Salvadorans for decades to come. This provides yet another reason for the government to heed the advice of local and international human rights advocates to end the country's extreme ban on abortion.



BRAZIL 

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 governmental 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."¹²³ 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."¹²⁴ She took the advice and began reaching out to other families who were affected by CZS. Not surprisingly, given the lack of quality 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."¹²⁵

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 even 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."¹²⁶ Through this inclusion, the rights of both parents and their children to health, family life, education, and social participation can be realized.



A Common Factor: Poverty and Development

As with many other infectious diseases, the spread and impact of the Zika virus is tied to social and economic inequalities in the Americas.¹²⁷ During on-site visits to all three countries, we saw untreated open sewage and storm drains that were creating unsanitary standing water conditions near the communities of women we directly 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 the virus.

A human rights-based approach was not always an explicit focus of Zika response efforts undertaken by global actors. Additionally, reproductive health and rights were mostly considered a supplementary rather than central issue. When international actors did take action to address reproductive health concerns, few came out strongly in favor of expanding access to abortion or, to a lesser degree, contraception. It is for this reason that a human rights-based approach in the response to Zika is critical—one that underscores the need to hold states accountable for upholding reproductive rights and disability rights as fundamental human rights in public health responses to Zika and other infectious diseases.¹²⁸

Government's Human Rights Obligations

Zika disproportionately burdens women's reproductive lives, particularly marginalized and low-income women, women living in remote and rural areas, and women of color. Prior to the Zika outbreak, these populations were already struggling to exercise control over their reproductive lives due to a lack of access to adequate reproductive health information, care, and services available to them. Additionally, the significant impact Zika has had on children and their parents carrying the virus has shined new light on the inadequate support available for children with disabilities, their families, and caregivers.

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 placed 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 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.¹²⁹ 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 (CESCR) developed the content of the right to the highest attainable standard of health in its General Comment No. 14,¹³⁰ 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.”¹³¹

The right to reproductive health includes:

The Right to Access Accurate and Comprehensive Information

U.N. Treaty Monitoring Bodies have recognized that the right to accurate and comprehensive information includes seeking, receiving, and imparting information and education on reproductive health.¹³² 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.¹³³ The disseminated information must be accurate, unbiased, and evidence-based so women can make informed decisions about things like pregnancy and parenting.¹³⁴



Information must also be disseminated in a timely and inclusive manner.¹³⁵ This means that states must ensure that this information reaches the poorest and most marginalized populations to dispel any rumors and misconceptions that may exist about Zika and its prenatal complications.¹³⁶ 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.

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.¹³⁷ 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.¹³⁸

Safeguarding women's autonomy and decision-making regarding their sexual and reproductive lives should be central to national, global, and regional responses to Zika.¹³⁹ 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 Convention on the Elimination of All Forms of Discrimination against Women explicitly recognize that the right to reproductive health includes the availability of contraceptive information and services.¹⁴⁰ 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.¹⁴¹ Requirements of third-party consent for access to contraception must be removed as internal human rights bodies have consistently considered such requirements contrary to women's rights.¹⁴²

The Right to Abortion

U.N. human rights bodies have recognized the negative consequences of restrictive abortion laws on women's health¹⁴³ and have consistently raised concerns about the inaccessibility of safe abortion services. As part of the comprehensive response to the Zika crisis, states must remove all legal and programmatic barriers for women to access safe abortion services. 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." As recognized by 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."¹⁴⁴

The Right to Quality Maternal Health Care

Should a woman decide to carry a pregnancy to term, states must ensure that they have access to quality maternal health care. Under international human rights law, states have an obligation to eliminate all types of discrimination that affect women, including those that affect them as a result of pregnancy.¹⁴⁵ According to the U.N. Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), "States parties shall ensure to women appropriate services in connection with pregnancy, confinement, and the post-natal period, granting free services where necessary."¹⁴⁶ In the case *Alyne da Silva Pimentel v. Brazil*, CEDAW recognized that quality maternal health care must be available for all women without discrimination, regardless of their race, income, or geographic location.¹⁴⁷ Therefore, states must ensure that women have access to maternal health care that is tailored to the unique risks associated with the Zika epidemic.

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).¹⁴⁸ CRPD states that people with disabilities are entitled to the full and equal enjoyment of all human rights and fundamental freedoms.¹⁴⁹ 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.¹⁵⁰

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."¹⁵¹ 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."¹⁵²

In addition, General Comment No. 5 of the U.N. Committee on Economic, Social, and Cultural Rights recommends that states ensure the provision of social security and adequate income support to people with disabilities and their caretakers.¹⁵³ CESCR 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."¹⁵⁴

States Prevention and Treatment Obligations

State parties have an obligation to take every measure required for the prevention, treatment, and control of epidemics.¹⁵⁵ Governments are mandated to establish “prevention and education programs for behavior-related health concerns,” particularly those that adversely impact an individual’s sexual and reproductive health.¹⁵⁶ 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.¹⁵⁷ 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.¹⁵⁸ 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.

The Right to an Adequate Standard of Living

In accordance with the International Covenant on Economic, Social and Cultural Rights, states parties are mandated to recognize the right to an adequate standard of living for everyone.¹⁵⁹ This includes the right to adequate food, clothing, housing and the continuous improvement of living conditions.¹⁶⁰ 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.¹⁶¹ 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.”¹⁶²

The Right to Water and Sanitation

Longstanding infrastructure problems have been found to have exacerbated the Zika outbreak in Latin America and the Caribbean.¹⁶³ 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 Nation 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.”¹⁶⁴ 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.¹⁶⁵

Key Recommendations



Governments Recommendations:

- Identify best practices to address the public health crisis using a human rights-based approach.
- Provide comprehensive sexual and reproductive health education to women of all socioeconomic backgrounds, with an emphasis on eliminating gender-based inequities and empowering women to make their own informed decisions.
- Support a woman's right to have children when she so chooses by making information available and creating safe conditions, such as providing quality maternal health care, distributing insect repellent, making treatments available, as well as controlling vector outbreaks and improving water and sanitation.
- Guarantee universal access to all forms of contraception and safe, legal abortion, especially in cases when the well-being of a pregnant woman is at risk or in cases of unwanted pregnancies, and ensure that pregnant women concerned about their pregnancy are counseled on their full range of options.
- Protect the rights of children with disabilities to have reasonable accommodations and equitable access to health care, inclusive education, and other support services and mechanisms.
- Develop training programs to ensure providers can implement Zika-related and sexual and reproductive health protocols.
- Enforce international human rights obligations in relation to women's reproductive rights.



Health Care System Recommendations

- Provide comprehensive counseling to all women of reproductive age on the pregnancy-related risks of Zika as well as all the reproductive options available to them free from personal biases.
- Guarantee quality reproductive, sexual, maternal, and pediatric care, including specialized monitoring for those at risk for Zika, both for women during pregnancy and their children after birth for at least the first few years.



International Organization Recommendations

- Affirm the importance of a human rights-based approach in dealing with public health crises, such as the Zika epidemic, and recognize the need to address gender inequality and disparities when confronting such challenges.
- Provide technical assistance to affected regions, including comprehensive sexuality education and sexual and reproductive health information and services using a human rights-based approach.
- Facilitate the development and sharing of best practices for Zika-related testing, diagnosis techniques, and eradication efforts.
- Support continued research on the long-term gendered impact of Zika and other epidemics and ensure knowledge sharing across organizations.



Donors Recommendations

- Prioritize supporting programs that address the underlying root causes, drivers, and impact of the Zika epidemic, including programs that focus on sexual and reproductive health and rights, disability rights, and access to clean water and sanitation.
- Provide support to programs that provide women with counseling and services on a complete range of reproductive health options, including contraception and safe abortion.
- Increase allocation of resources to organizations and programs that advocate for the respect, promotion, and protection of a woman's sexual and reproductive health and rights, and that provide sexual and reproductive health information and services.
- Remove funding restrictions that limit sexual and reproductive rights.
- Support services that help protect the human rights of individuals living with disabilities, including those related to Zika, and facilitate their full participation in society.



Private Sector Recommendations

- Partner with governments, the health sector, and civil society to provide services to populations affected by Zika, including the distribution of insect repellent and the provision of free or fairly-priced treatments, medicines, vaccines, and comprehensive health care services.



Non-Governmental Organization Recommendations

- Support the advancement of human rights by recognizing the impact that a person's socioeconomic status, gender, and race has on their experience with Zika.
- Support community engagement and adjustments within the health system to make Zika-related services accessible.
- Engage in interdisciplinary, qualitative, and quantitative research efforts on the impact of Zika, leading to evidence-based recommendations and best practices that inform law and policy makers.
- Partner with other civil society organizations to share data and build coalitions with other movements, such as the disability rights movement, and other strategic partners, such as the private sector.



Conclusion

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

Unfortunately, our research showed few signs that lasting changes were being made in Latin American and the Caribbean, with a special emphasis on Brazil, Colombia, and El Salvador, to address the shortcomings of their health care systems in adequately protecting women's reproductive health and the rights of people with disabilities.

While there remains the possibility that positive policy changes could emerge as governments and their citizens reflect on the epidemic and its impact, this seems increasingly unlikely. The stories detailed in this report highlight the limited extent that women's perspectives were taken into consideration during the outbreak. Through their stories, it has become apparent that countries did not adequately ensure that women had the tools necessary 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, further exacerbating existing inequalities.

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.
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- 121 CENTER FOR REPRODUCTIVE RIGHTS (CRR), MARGINALIZED, PERSECUTED, AND IMPRISONED – THE EFFECTS OF EL SALVADOR'S TOTAL CRIMINALISATION OF ABORTION 14 (2014) [hereinafter CRR, MARGINALIZED].
- 122 United Nations Human Rights Office of the High Commissioner, *Statement by UN High Commissioner for Human Rights Zeid Ra'ad Al Hussein at the end of his mission to El Salvador* (Nov. 17, 2017); CEDAW Committee, *Concluding Observations: El Salvador*, paras. 36 & 37, U.N. Doc. CEDAW/C/SLV/CO/8-9 (2017).
- 123 Interview with Joana, *supra* note 12.
- 124 *Id.*
- 125 *Id.*, at [0:00, "Estava recebendo as pessoas sem saber nada...porque foi uma situacao de supresa. Ninguem tava preparado para isso."]
- 126 *Id.*, at [38:30, "A gente acredita que a gente vai construir uma sociedade mais igualitaria...que as pessoas aceitam mais as crianças. Nosso objectivo é isso - ter espaço de inclusao nas pracas - ter espaço de inclusao nas escolas."]
- 127 See, e.g., PAUL FARMER, INFECTIONS AND INEQUALITIES: THE MODERN PLAGUES (2001); Michael J. Selgelid, *Justice, Infectious Diseases and Globalization*, in 7 GLOBAL HEALTH AND GLOBAL HEALTH ETHICS 89, 89 (Solomon Benatar and Gillian Brock eds., 2011); Lara Stemple et al., *Human Rights, Gender, and Infectious Disease: From HIV/AIDS to Ebola*, 38 HUMAN RIGHTS QUARTERLY 993 (2016).
- 128 CRR, CENTERING HUMAN RIGHTS IN THE RESPONSE TO ZIKA (2016).
- 129 The right to the highest attainable standard of health is recognized in numerous international instruments, including the *Universal Declaration of Human Rights* and the *International Covenant on Economic, Social and Cultural Rights*. This right is also recognized in the *International Convention on the Elimination of All Forms of Racial Discrimination*, the *Convention on the Elimination of All Forms of Discrimination against Women*, the *Convention on the Rights of the Child*, and the *Convention on the Rights of Persons with Disabilities*. In the regional context, the right to health is also protected under

- the *Additional Protocol to American Convention on Human Rights in the Area of Economic, Social and Cultural Rights*.
- 130 Committee on Economic, Social and Cultural Rights (ESCR Committee), *General Comment No. 14: The Right to the highest attainable standard of health (Art. 12)*, (22nd Sess., 2000), U.N. Doc HRI/GEN/1/Rev.9 (Vol. I) (2008) [hereinafter ESCR Committee, *Gen. Comment No. 14*].
- 131 See *Id.*, the definition of reproductive health provided by the Office of the High Commissioner for Human Rights in *Article 12.2(a): The Right to maternal, child and reproductive health* in footnote 12 of the ESCR *Gen. Comment No. 14*.
- 132 CRC, *Gen. Comment No. 4*, *supra* note 118 para. 28; ESCR Committee, *Gen. Comment No 14*, *supra* note 130 para. 34; CEDAW Committee, *General Recommendation No. 21: Equality in marriage and family relations*, (13th Sess., 1994), para. 22, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II) (2008).
- 133 CRR, *supra* note 128, at 2.
- 134 *Id.*
- 135 *Id.*, at 1-4.
- 136 *Id.*
- 137 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), *adopted* Dec. 18, 1979, art. 16(1)(e), G.A. Res. 34/180, U.N. GAOR, 34th Sess., Supp. No. 46, at 193, U.N. Doc. A/34/46 (1980), U.N.T.S. 13 (*entered into force* Sept. 3, 1981); see also Convention on the Rights of Persons with Disabilities (CRPD), *adopted* Dec. 13, 2006, art. 23(1)(b), G.A. Res. A/RES/61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/61/611 (1980), Annex I (*entered into force* May 3, 2008) [hereinafter CRPD].
- 138 International Covenant on Civil and Political Rights, *adopted* Dec. 16, 1966, art. 17, paras. 1–2, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (*entered into force* Mar. 23, 1976); see also Convention on the Rights of the Child, *adopted* Nov. 20, 1989, arts. 16(1–2), 22(1), G.A. Res. 44/25, annex, U.N. GAOR, 44th Sess., Supp. No. 49, U.N. Doc. A/44/49 (1989) (*entered into force* Sept. 2, 1990) [hereinafter CRC]; American Convention on Human Rights, *adopted* Nov. 22, 1969, art. 11, para. 2, O.A.S.T.S. No. 36, O.A.S. Off. Rec. OEA/Ser.L/V/II.23, doc. 21, rev. 6 (*entered into force* July 18, 1978).
- 139 CEDAW Committee, *General Recommendation No. 25: Temporary Special Measures*, (30th Sess., 2004), para. 9, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II) (2008).
- 140 ESCR Committee, *Gen. Comment No 14*, *supra* note 130; CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, (20th Sess., 1999), para. 17 U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II) (2008) [hereinafter CEDAW Committee, *Gen. Recommendation No. 24*]; CEDAW Committee, *Gen. Recommendation No. 21*, *supra* note 133.
- 141 See the definition of reproductive health, ESCR Committee, *Gen. Comment No. 14*, *supra* note 130.
- 142 CEDAW Committee, *Gen. Recommendation No. 24*, *supra* note 141, para. 14; CEDAW Committee, *Concluding Observations: Indonesia*, para. 16, U.N. Doc. CEDAW/C/IDN/CO/5 (2007); CRC Committee, *General Comment No. 15: on the right of the child to the enjoyment of the highest attainable standard of health (art. 24)*, (62nd Sess., 2013) U.N. Doc. CRC/C/GC/15 (2013); *Id.*, para. 31.
- 143 See, e.g., Human Rights Committee, *Concluding Observations: Argentina*, para. 14, U.N. Doc. CCPR/CO/70/ARG (2000); CEDAW 1999, *supra* note 6, pt. 2, ch. IV, Chile, para. 228; CEDAW 1999, *supra* note 6, pt. 1, ch. IV, C [GS/SexualHealth/INFO_Abortion_WEB.pdf](#).
- 144 See, e.g., Human Rights Committee (hereinafter ‘CCPR’), *Concluding Observations: Mali*, para. 14., U.N. Doc. CCPR/CO/77/MLI (2003); CCPR, *Concluding Observations: Poland*, para. 11, U.N. Doc. CCPR/C/79/Add.110 (1999); CAT Committee, *Concluding Observations: Chile*, para. 7(m), U.N. Doc. CAT/CR/32/5 (2004).
- 145 ESCR Committee, *Gen. Comment No. 14*, *supra* note 130, para. 21.
- 146 CEDAW, *supra* note 138, art. 12(2).
- 147 *Alyne da Silva Pimentel Teixeira v. Brazil*, CEDAW Committee, Commc’n No. 17/2008, at 21, U.N. Doc. CEDAW/C/49/D/17/2008 (2011).
- 148 See CRPD, *supra* note 138.
- 149 See *Id.*, art. 1; See also Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, *adopted* Jun 7, 1999, art. II, 29th Sess., U.N. Doc. AG/RES. 1608 (XXIX-O/99) (*entered into force* Sept. 14, 2001).
- 150 CRPD, *supra* note 138, art. 2, para. 5.
- 151 CRC, *General Comment No. 9: The rights of children with disabilities*, (43rd Sess., 2006), para 41, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II) 2008.
- 152 *Id.*
- 153 ESCR Committee, *General Comment No. 5: Persons with disabilities (Art. 11th Sess., 1994)*, para 28, U.N. Doc. HRI/GEN/Rev.9 (Vol. I) (2008).
- 154 *Id.*
- 155 ICESCR, *supra* note 144 art. 12(c).
- 156 ESCR Committee, *Gen. Comment No. 14*, *supra* note 130 at para. 16.
- 157 *Id.*
- 158 *Id.*
- 159 ICESCR, *supra* note 144, art. 11, para. 1.
- 160 *Id.*
- 161 ESCR Committee, *General Comment No.4: The Right to Adequate Housing (Art.11 (1) of the Covenant)*, (6th Sess., 1991), para. 8, U.N. Doc. E/1992/23 (1991).
- 162 *Id.*
- 163 Margaret Wurth, *Brazil’s Zika Threat Remains: Water, Sanitation Problems That Intensified Zika Outbreak Persist*, HRW (May 12, 2017) [hereinafter Wurth].
- 164 G.A. Res. 70/169, *The human rights to safe drinking water and sanitation*, at 4 (Feb. 22, 2016).
- 165 Wurth, *supra* note 167.



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