



# ZIKA IN BRAZIL

Reproductive Justice in Response  
to a Humanitarian Crisis

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Patricia and her children, 2018

**Zika in Brazil: Reproductive Justice in Response to a Humanitarian Crisis**

This report was produced by Anis – Institute of Bioethics, Brasília/DF, Brazil

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Alessandra and Sara, 2018

## 2020: THE ZIKA LEGACY AND THE COVID-19 PANDEMIC

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The demands of the Zika crisis remain relevant and are exacerbated by COVID-19. **In 2020 alone, according to data recorded up to June, there have already been 468 reported cases of children in Brazil who are suspected to have congenital Zika syndrome – an average of more than two cases a day.**

The Ministry of Health acknowledged in its [July 2020 epidemiological bulletin](#) on the topic that "even though the emergency situation has ended for Zika, new cases of CZS [congenital Zika syndrome] continue to occur in the country".

In August 2020, the Brazilian Ministry of Health published concerning data regarding pregnancy and infant outcomes of women confirmed for Zika virus infection during gestation. They found much lower than expected rates of Zika-related outcomes. The alarming low number of CZS and congenital anomalies detected is suggestive of significant epidemiological surveillance and public health failures.

For women, girls, children, and families affected or at risk of being affected, Zika is an endless epidemic that still requires continuous and adequate local and national actions to protect their rights.

Zika-affected women were once again not included in the main responses to the humanitarian crisis caused by the COVID-19 pandemic. To ignore the needs of women and girls is to reproduce inequalities and injustices. With multiple health needs, children become more vulnerable to the harmful effects of illness due to SARS-CoV-2. But there are no specific protection and care policies for women and children during the pandemic.

## DIÁRIO de PERNAMBUCO

Sobreviventes de uma epidemia, crianças com microcefalia enfrentam desafios de uma pandemia

Por: [Márcia Teles](#) | Publicado em: 15/04/2020 14:11 | Atualizado em: 15/04/2020 14:22



Survivors of an epidemic, children with microcephaly face the challenges of a pandemic. Published in: 04/15/2020

THE ZIKA EPIDEMIC USHERED IN A NEW MOMENT IN THE DISCUSSION ON INTERSECTIONALITY FOR THE PROTECTION AND DEFENSE OF REPRODUCTIVE JUSTICE IN LATIN AMERICA AND THE CARIBBEAN.

Zika, a virus transmitted by the *Aedes aegypti* mosquito, has been around since the 1940s, but only reached the Americas in 2014 via Brazil. The virus encountered ideal conditions for proliferating in most countries in the region due to the presence of the mosquito vector, which transmits other endemic infections such as dengue, yellow fever, and chikungunya. **Zika infection can also be transmitted sexually and, in 2015, reports began to emerge about the possibility of vertical transmission from pregnant women to fetuses** and possible subsequent neurological complications.

A few months after the confirmed circulation of the Zika virus in Brazil, there were reports of a growth in the number of newborns with microcephaly and other neurological complications: in 2015, there was a **1,923% increase** in reports of microcephaly cases in newborns compared to the previous year.

Zika became a torment for pregnant women who, upon becoming sick, feared the vertical transmission of the virus and the risk of serious complications. A few months later, in February 2016, the [World Health Organization \(WHO\)](#) declared Zika a Public Health Emergency of International Concern (PHEIC).

It was the first time that such a declaration had been made for an infection that had specific effects on the reproductive process.

Given this scenario, it should have been unthinkable to ignore girls and women in the responses to the Zika virus and its consequences, but that is exactly what happened. Even with the United Nations recommendation that governments of Zika-affected countries allow access to abortion and contraceptive methods, countries like [Brazil and El Salvador](#) recommended postponing pregnancy or practicing sexual abstinence, disregarding the region's [high rate of unintended pregnancy](#).

**There was no change in policies on access to sex education and modern contraceptive methods in the immediate response to Zika. Nor did the countries enact any structural changes in social protection policies for mothers or for children with disabilities.**

In the case of Brazil and several other countries, the main campaigns promoted by federal governments focused on the mosquito as the enemy to be combated, while little was done to respond to the needs of women already affected by the epidemic and to protect the health of those still vulnerable to infection. To make matters worse, the

majority of countries affected by Zika maintained the criminalization of abortion, with its accompanying threat of jail or risk of death for women who, fearing the virus and its effects, could not continue a pregnancy.

Although Zika infections were reported in [87 other countries and territories as of July 2019](#), Brazil was the epicenter of the crisis and its consequences. [By August 2020](#), of the more than five million cases of Zika virus in the Americas since the onset of the epidemic in 2015, almost a quarter of those cases (1,250,371) were registered in Brazil.

In response to the emergency, Anis – Institute of Bioethics created a constellation of responses to the public health crisis that had revealed itself to be a mirror of inequalities in the country; inequalities of gender, race, class, and region.

**In this report, we will draw from the experiences we gained over the last five years to share how we put into practice some of our main activities to guarantee reproductive justice for women and girls both during and after an epidemic.**

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What can we do when the intersectional needs of women and girls are not included at the center of the response to a humanitarian crisis?

**1. Build narratives that portray the effects of the crisis on the lives of women and girls**

**2. Provoke the implementation of evidence-based public policies**

**3. Catalyze advocacy for legal and policy review**



Erik, Alessandra, Alexsandra and Maria, 2016

## 1. **BUILDING NARRATIVES:** WOMEN AND GIRLS AT THE CENTER OF THE ZIKA CRISIS

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The media intensely covered the beginning of the Zika crisis in Brazil between November 2015 and July 2016. The “microcephaly outbreak” was in the daily newspapers with updated figures about the births of “small-headed babies”. While there was substantial attention from the media, there were problems with the framing. The focus was on children and images of malformations and the discussion was of “a lost generation”. While inappropriately

depicting disability as a tragedy, little was said about the women and girls who were experiencing the anguish of being pregnant during the epidemic. There were reports of elite families who had been able to choose to migrate abroad for the duration of their pregnancies.

**Girls and women of reproductive age had been ignored.**

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**In order to shift the framework, it was necessary to transform women and girls into the protagonists of the reports. Some guiding principles were:**

- **The recording of stories** using videos and images for social networks and other media
- **Dissemination to broadcast** the stories of women from the communities we work with

## IMPACT ON THE MEDIA

From 2015 to 2020, **735 articles** were published in the national and international media with reference to Anis' work related to Zika. These pieces featured interviews with the Anis team, data from our survey or stories from the communities with which we work. If that media space had been acquired commercially, it would have cost **2.520.536,15 dollars**.

The New York Times

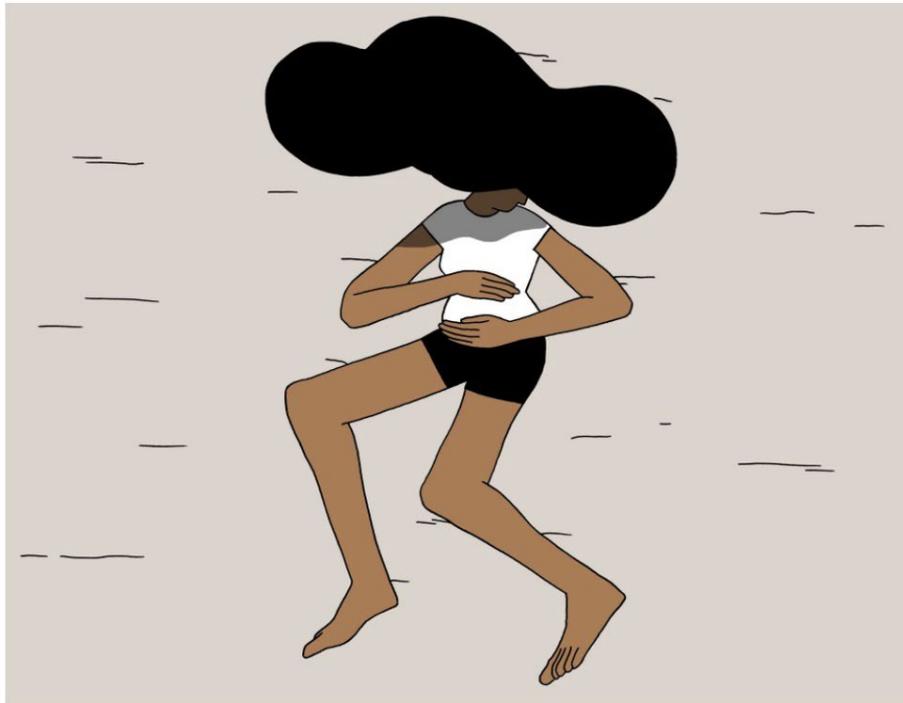
Opinion

OP-ED CONTRIBUTOR

# The Zika Virus and Brazilian Women's Right to Choose

By Debora Diniz

Feb. 8, 2016



Marie Guillard

**The Zika Virus and Brazilian Women's Right to Choose**, a *New York Times* article by Debora Diniz published in the week of the WHO PHEIC announcement, in February 2016.

In the face of a public health emergency, it is important to tell stories that put women and girls at the center of responses to the crisis and its consequences.

Narratives are more effective than raw data: they allow us to imagine how problems are actually being experienced, and they can stir people's moral concerns and move them to take action. The thesis of the "microcephaly outbreak" was made real by the images of children spread by the media, accompanied by images of mosquitoes.

Between February and March 2016, a few weeks after the WHO announcement that Zika was a Public Health Emergency of International Concern, the Anis team traveled to the epicenter of the country's epidemic to collect and to share the stories of women surviving the Zika epidemic. **Our first step was to produce a documentary about the story of five of these women.**

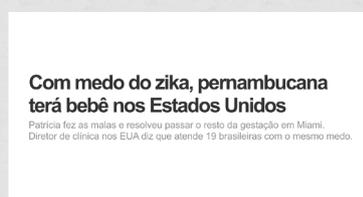
Among them was the first woman to donate amniotic fluid that was then used to identify the virus in the placenta. Science at that time was scrambling for answers, but behind the statistics

and samples of blood and fluid were real women like Gécica dos Santos, who suffered the neonatal death of her baby as a result of the Zika virus.

The women were the faces of Brazilian inequality. Their basic life needs had become urgent necessities because the country was insensitive to the intersectional inequalities of class, race, and gender. Violations of reproductive justice were present throughout their stories. They were women who had traveled more than five hours to obtain treatment for their children, women without access to information about sexual and reproductive rights, religious women who had had to terminate their pregnancies because of the risk to their lives, and families without social assistance.

The film quickly became a reference for understanding how the main victims of Zika lived. Through the women's stories, it was possible to provide faces and personal histories to support the assertion that Zika had exacerbated pre-existing problems that had resulted from State neglect and inequality.

The women were the first to watch the documentary and to approve its screening.



Afraid of Zika, a pernambucana [a woman from Pernambuco] will have her baby in the United States



Babies victims of Zika have brain lesions in addition to microcephaly



Understand the other complications in babies associated with microcephaly and Zika



Microcephaly epidemic in Brazil: "The ultrasound showed that my son's head stopped growing."



The documentary has had over **46,000 views on YouTube**, with subtitles in [Portuguese](#), [English](#), and [Spanish](#). It was shown at several events throughout Brazil and in international fora.



### **Marina Leite**

Marina had mild symptoms of Zika during her second pregnancy but was not diagnosed at the time she fell ill. When Marina had her first ultrasound, she found out that there was something wrong with the development of the fetus. During her prenatal care, it was determined that continuing with the pregnancy could put her health and life at risk. Marina describes herself as a woman of faith, and even though she is Catholic, she decided to have a legal abortion to save her life.



### **Géssica dos Santos**

Géssica had symptoms early in her pregnancy. In the twentieth week, she discovered that her future child had a fetal malformation. In February 2016, she gave birth to a baby boy who died a few hours after birth. She decided to donate her son's body to science to allow further research into the effects of Zika on fetuses. The first identification of the Zika virus in amniotic fluid came from Géssica's gesture of solidarity with humanity.

THE INTERPRETER

## *How YouTube Misinformation Resolved a WhatsApp Mystery in Brazil*



Luciana Brito

The New York Times, August 2019.

### **Stories are also important for pushing a topic back onto the political agenda.**

After the WHO decreed the end of the Public Health Emergency of International Concern in November 2016, Zika disappeared from public discussion.

There was a need to find ways to:

1. tell stories about the continued effect of Zika on the lives of women and families, and
2. connect the rights violations related to Zika to other topics on the political agenda to ensure that the demands of the most affected populations gained visibility.

These objectives have become a permanent commitment to the communities with which we have worked for the past five years. In 2019, we collaborated, for example, on the production of an in-depth article and mini-documentary for the newspaper [Metrópoles](#) about women in central Brazil who are living with children affected by Zika. This was a region of the country where Zika was thought to not have reached, so the purpose of the

coverage was twofold: to show that the effects of the epidemic had been territorially more extensive than previously assumed, and to present the various needs caregivers and children faced as the children grow up. Both frameworks were necessary for the families to be able to vindicate their rights vis-a-vis the local governments.

In 2019, we also collaborated with [The New York Times](#) on a report about how fake news about Zika and the mistrust in science were mobilized as tools of political extremism that fuel an ecosystem of hate in Brazil.

Since Jair Bolsonaro won the 2018 presidential election, the advance of the Brazilian extreme right has been a topic of interest to the international press, such that highlighting his abandonment of Zika victims was another way of pushing the discussion back onto the agenda. The report also emphasized how disinformation increases the vulnerability of families affected by Zika, impeding their adequate access to health care and their ability to vindicate their rights.

As we did at the beginning of the crisis, we determined that it was essential to continue to produce narratives of women sharing how they were living years after they had been infected and given birth to their children. Accordingly, in 2019, we produced short videos

with stories of women living the legacy of the Zika epidemic. The short videos have allowed for wider reach, engagement, and circulation on social networks. The videos are available on YouTube, with subtitles in Portuguese, English, and Spanish.



**Ana Lúcia Mota** [reflects on the importance of the community association in Alagoas](#), Brazil for securing social rights and accessing health care. She is the grandmother of Dayara, a child with congenital Zika syndrome.

**Alessandra dos Santos** [speaks about how the creation of an association of women affected by Zika](#) has been instrumental in strengthening community engagement among women.



**Lenice do Nascimento** is the mother of Enzo, a school-age child affected by Zika. [She talks about the importance of a school that is accessible to children with disabilities](#), and how school has played an important role in enabling her to plan a return to paid work.



## 2. ELICITING THE IMPLEMENTATION OF EVIDENCE-BASED PUBLIC POLICIES: WHAT ARE THE NEEDS OF GIRLS AND WOMEN AFFECTED BY THE ZIKA CRISIS?

Individual stories allowed us to get close to the problem and to show how it was urgent and important, while the data showed the vastness of the effects we described. Showing the magnitude of the rights violations that resulted from the crisis, accompanied by the

faces and voices of women and girls, can play a transformational role in incorporating the ethics of reproductive justice in the approaches to the epidemic. These can be fundamental actions for advocacy activities at the national or regional level.

**There are various methods for producing evidence about a public health emergency or humanitarian crisis, and each organization can use those methods with which it is most familiar:**

- **To persuade their countries** to provide official data on the effects of the health emergency, with stratification by gender, age, race, education, disability, region, and other available indicators;
- **To collect data** through the provision of services; and
- **To conduct research** with the communities you work with or to align themselves with partner organizations that are capable of producing such research.

# Alagoas

12/31/2016

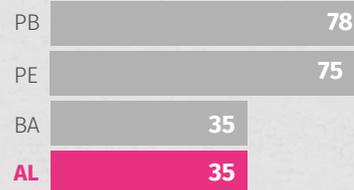
**371** CASES  
**3.6%** OF NATIONAL TOTAL  
**86** CONFIRMED CASES  
**51** CASES UNDER INVESTIGATION  
**234** DISCARDED CASES

## CASES

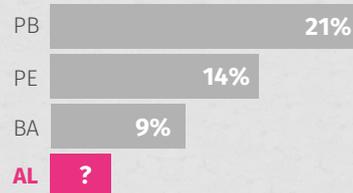
CONFIRMED  
 UNDER INVESTIGATION  
 DISCARDED



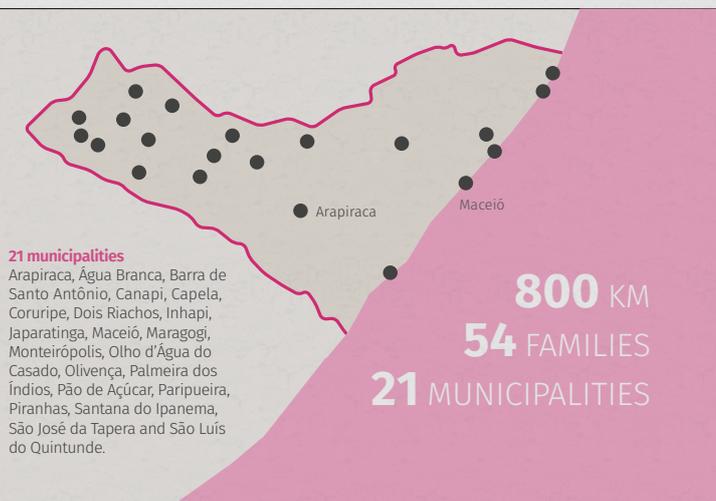
## CASES/10,000 LIVE BIRTHS 2015 to 2016



## ACCUMULATED PREVALENCE OF CHILDREN AFFECTED BY ZIKA 2015 to 2016



## Maria Bonita Expedition | Alagoas



This case study was funded by Wellcome Trust, project "Care, health and stigma among families affected by the Congenital Zika Syndrome"

Persuading the State to provide answers and evidence on ways of protecting the populations most vulnerable to Zika was one of Anis' initial strategies, and it quickly became evident that in Brazil there was no specific policy for women and girls affected by Zika. This would become an advocacy path for us, and an area in which we collected additional evidence.

In an effort to collect such evidence, we initiated a case study in the state of Alagoas, which was one of the states at the epicenter of the epidemic and which has both the lowest Human Development Index (HDI) and the highest teenage pregnancy rate in the country. In December 2016, guided by a list of the municipalities that had reported cases to the Ministry of Health, we visited 54 women and listened to their stories. At that time, there were 86 women in the state whose children had been confirmed as having a Zika-related diagnosis. **The expedition allowed us to chronicle the precariousness of the lives of women and children affected by the epidemic, their needs, and the violations of their rights.**

During the expedition, we found that most of the affected women were young and Black, and that three out of four had been teenage mothers and had had little schooling. Half of the women did not use any contraceptive method, even though they did not intend on getting pregnant again, and none of the women had returned to paid work.

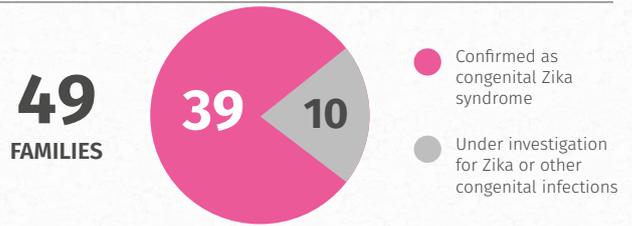
Half of the children needed continuous access to medication, but half of them did not receive it from the public health system. There were also children without any specialized assistance.

In addition to the evidence produced at the beginning of the epidemic to understand the needs of girls and women, we have also focused on understanding the legacy of the Zika crisis after the epidemic ended.

**Presenting evidence in credible scientific journals with data about women's access to sexual and reproductive health is also part of an advocacy strategy.**

During qualitative research with young women living in regions considered to be the epicenter of the epidemic, we found that half of the women had had a pregnancy during adolescence, and all had faced some type of barrier to accessing sexual and reproductive

**Number of families interviewed**  
Maria Bonita Expedition

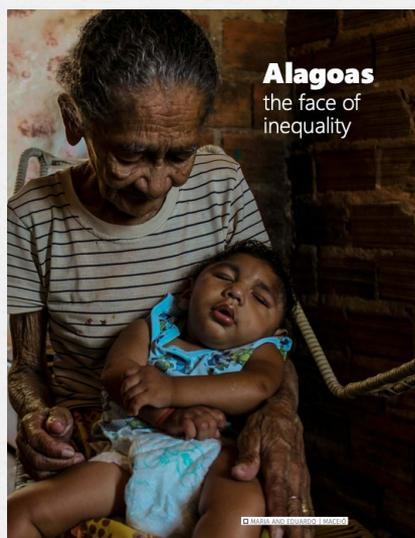


health services. Many did not know about long-term contraceptive methods and almost none knew that the Zika virus was also a sexually transmitted infection.

Currently, these women are facing a second public health emergency, the COVID-19 pandemic. That is why it is important to reflect on the lessons learned in facing the humanitarian crisis imposed by the Zika epidemic to develop strategies to guarantee sexual and reproductive rights for girls and women and protections in the post-pandemic future.



**Zika in Brazil**  
women and children at the center of the epidemic



**Alagoas, the face of inequality**  
Maria and Eduardo | Maceió



**Eder and Katlyn | Maceió**  
"I'm a waiter, I earn little, the money is only enough for food and her diapers. I would rather go hungry than see my daughter crying ... crying with hunger. I would rather go hungry than see my daughter go hungry. Her life is not easy."



## Understanding sexual and reproductive health needs of young women living in Zika affected regions: a qualitative study in northeastern Brazil

[Debora Diniz](#), [Moazzam Ali](#) , [Ilana Ambrogi](#) & [Luciana Brito](#) 

*Reproductive Health* 17, Article number: 22 (2020) | [Cite this article](#)

**Article published with results of a survey conducted by Anis** on the sexual and reproductive health needs of women living in Brazilian regions affected by Zika. The research was supported by the World Health Organization (WHO/HRP)

### Re: The end of Brazil's More Doctors programme?

Brazil continues to be the epicenter of the global outbreak of Zika virus. In 2018, there were 78 confirmed new cases of children affected by Zika, 63 cases considered probable for Zika and 823 still under investigation as Zika affected cases. In total there are 16 735 notified newborns since the beginning of monitoring of the cases in November of 2015 until October 2018. Of these, 3 267 were confirmed to have Congenital Zika Syndrome (CZS), 569 are probable cases and 2 769 cases still under investigation. Only 35% of the children with confirmed CZS are receiving early stimulation services, and only 63% of them are getting specialised care and 39% of them are not even getting routine paediatric care[2].

**21 December 2018**

**Ilana G Ambrogi**

Medical Doctor

Debora Diniz; Luciana Brito

Brasilia, Brazil

[@anis\\_bioetica](#)

**Letters to the editors** about the Zika crisis in Brazil to The British Medical Journal, 2018

# COALITION WITH INTERNATIONAL AGENCIES, FEMINIST AND HUMAN RIGHTS ORGANIZATIONS FOR JOINT ADVOCACY

## Zika and Women's Rights Situation Room

In 2016, the Situation, Action and Articulation Room on Women's Rights, Sexual and Reproductive Rights in Zika Times was created by UN Women, the Pan American Health Organization (PAHO/WHO), and the United Nations Population Fund (UNFPA). Anis and other feminist and human rights organizations participated actively in the meetings. Six meetings took place between 2016 and 2017 during the Zika epidemic. This space became an open channel for feminist and women's organizations for the analysis of research and information on health and for joint actions between civil society and the United Nations.

The Situation Room was an important space for the defense of the rights of women and children with local authorities, as well as a space for dialogue on how to guarantee these rights and improve sexual and reproductive health services during the epidemic.

The organizations that acted in partnership were fundamental for the composition of an ecosystem of mutual learning in an intersectional perspective that encompassed aspects about race, ethnicity, gender, disability, the environment, and social justice. The organizations include:



Sala de Situação sobre Zika e Direitos das Mulheres completa um ano e se firma como prática inovadora de resposta à crise sanitária

19.06.2017

Nas Américas e Caribe, Brasil foi país com maior incidência da epidemia do vírus zika. Com o fim da emergência nacional, declarada pelo país, neste zika, persiste o desafio de atender as mulheres mais vulneráveis aos efeitos da epidemia. Clique aqui para saber sobre as ações da ONU Mulheres Brasil sobre zika e direitos das mulheres

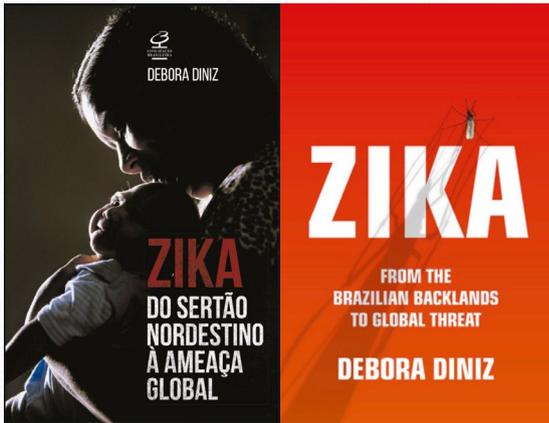


[UN women Brazil](#)

**Zika and Women's Rights Situation room completes a year of existence and establishes itself as a humanitarian crisis response innovative practice | 05/19/2017**

In the Americas and the Caribbean, Brazil was the country with the highest incidence of the Zika virus epidemic. With the end of the national emergency declared in the country this month, the challenge of caring for women most vulnerable to the effects of the epidemic persists.

- [AADS – Ações Afirmativas em Direitos e Saúde](#)
- [GEA - Grupo de Estudos sobre Aborto](#)
- [Gestos](#)
- [Grupo Curumim](#)
- [Instituto Odara](#)
- [Instituto Patrícia Galvão](#)
- [IPAS](#)
- [Mirim Brasil](#)
- [Rede Feminista de Saúde](#)
- [Redeh – Rede de Desenvolvimento Humano](#)
- [Reprolatina](#)
- [Reprotai](#)
- [Uiala Mukaji](#)
- [ABRASCO – Associação Brasileira de Saúde Coletiva](#)
- [Católicas pelo Direito de Decidir](#)
- [CFEMEA – Centro Feminista de Estudos e Assessoria](#)
- [CEPIA – Cidadania, Estudo, Pesquisa, Informação, Ação](#)
- [CLADEM – Comitê Latino-Americano e do Caribe para a Defesa dos Direitos da Mulher](#)
- [Coletivo Mangueira](#)
- [Criola](#)



## Book “Zika: From the Brazilian Backlands to Global Threat ”

During 2016, the Anis team collected data about the process of Brazilian researchers, doctors, and women discovering the Zika virus and its effects on pregnancy. The work of collecting and systematizing that information gave rise to the book authored by Debora Diniz, Zika: From the Brazilian Backlands to Global Threat. Published in 2017, the book received the Jabuti award, the most prestigious Brazilian literary award, in the Health Sciences category.

The book was translated into [English](#) and [Japanese](#), and has become an important tool for strengthening ties with the community of health professionals and researchers in the biomedical fields, nationally and internationally. The book, written in accessible language, helped to popularize the story of the virus's arrival in the country as the story of a crisis with women as the protagonists.



## New Evidence Drives Health Protection

Despite the end of the PHEIC in 2016, women and girls still live the legacy of the Zika epidemic. Based on the evidence gathered during our research, we presented a report with recommendations for action for different spheres of government at the municipal, state, and federal levels.

The report also gave rise to the [first task force in the state of Alagoas](#) to review the cases identified by the epidemiological surveillance system - children from the countryside and the city were referred to the reference hospitals for tests. More than 60 cases that had been discarded at the beginning of the epidemic were reevaluated and almost half of them were considered to be confirmed cases and then incorporated into state efforts.

### Mutirão com profissionais da saúde reavaliam crianças notificadas com zika em Alagoas

MAIS INFORMAÇÕES [Twitter](#) [Curtir 0](#)



Task force of health professionals reevaluates reported Zika cases in Alagoas



Tayanne and Izabela, 2018

### 3. COMMUNITY MOBILIZATION AND STRATEGIC LITIGATION TO PROTECT RIGHTS

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**It is not sufficient to show that an epidemic violates rights: it is necessary to also demand that those rights be fulfilled. Some possible strategies are:**

- **To promote community mobilization activities** to build demands around unmet needs and violated rights;
- **To strengthen local leadership strategies**, either by promoting training activities and capacity building, formalizing community associations or facilitating links with other relevant actors; and
- **To propose strategic litigation** actions in local or international courts. Actions can be about paradigmatic individual cases or collective action cases.

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Strategic litigation, whether through individual paradigmatic cases or class actions, can be an important tool for ensuring government accountability for negligence in protecting the populations most vulnerable to public health emergencies. In August 2016, we joined with the National Association of Public Defenders (ANADEP) to file a petition at

the Brazilian Supreme Court to protect the rights violated by Zika: Direct Action of Unconstitutionality (ADI) no. 5581.

It is possible that the Direct Action of Unconstitutionality (ADI) 5581 was the first constitutional case in the country based on a holistic perspective of reproductive justice and disability justice: the lawsuit encompassed

not only the legal viability of the decision of whether or not to become a mother, but also the access to information and material resources that are needed to carry out one's decision, either to prevent or terminate a pregnancy, or to care for a future child with multiple disabilities.

To be able to write a petition on such a complex and new issue, we needed to not only listen to the women most affected by the epidemic to fully understand their needs, but to also articulate these needs with diverse movements and specialists from interdisciplinary fields.

Through community mobilization activities in the areas most affected by Zika, we came to understand that it was not possible to dissociate the various demands. For example, there was no way to demand access to health care without also talking about transportation, nor to demand protection for the reproductive decisions of women and girls without guaranteeing access to income and social protection programs for children with disabilities.

The collaboration with specialists, in turn, allowed us to add substance to these demands, via the use of **reliable evidence** about the effects of Zika that were being discovered in real time.

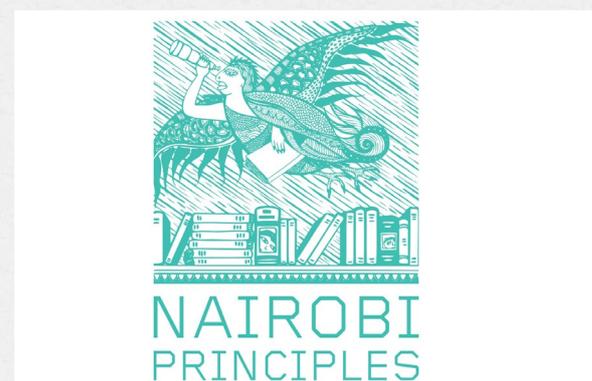
In a coordinated **effort to organize evidence for advocacy**, several technical opinions specifically written on the issue were annexed to the initial petition.

## The Intersectionality Between the Demands for Reproductive Rights and Disability Rights

Anis' previous experience in research and advocacy on issues of reproductive rights and the protection of the rights of people with disabilities facilitated the proposal for interconnections between the two movements in the face of the Zika crisis. In February 2016, Anis [held a debate](#) with the organization Down Movement on the compatibility between the demand for decriminalization of abortion for women affected by Zika and social policies to protect those with disabilities.



Anis' researchers with disabilities also engaged in the debate, [producing analyses](#) on the convergence between feminisms, abortion rights, and the protection of life and autonomy of people with disabilities, without recourse to criminal law.



In 2018, [Anis also participated in the global dialogue](#), in partnership with the organization CREA, that resulted in the Nairobi principles on abortion, prenatal testing, and disability. In this space we had the opportunity to bring to the global arena the intersectional experience of advocacy on Zika in Brazil.

## DEMANDS OF ADI 5.581

### **For women and children already affected by the epidemic, ADI 5581 called for social policies to protect mothers and children:**

- Access to the Continuous Cash Benefit (BPC), the country's most important income transfer program for people with disabilities, for all affected children and their caregivers, without maximum income criteria; and
- Access to early stimulation programs for children with congenital Zika syndrome at Specialized Rehabilitation Centers (CERs) located within a distance of up to 50 km from the family's residence, or paid transportation for families living 50 km or more from a center (TFD program).

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### **For the general population, but especially for adolescents and women of reproductive age, ADI 5581 demanded:**

- Access to up-to-date and quality information on current medical knowledge about the Zika virus epidemic, as well as methods of prevention. The petition specifically demanded that federal public authorities implement an effective public education program on how the virus is transmitted (including through sexual transmission), known and

not yet known effects of the epidemic, and contraceptive methods available in the public health system for women who want to prevent pregnancies. Relevant information should be made available on official federal government websites and in materials destined for schools and health services.

- Access to family planning programs and reproductive health care, with distribution in the public health network of long-term reversible contraceptives, such as the IUD with the release of the hormone levonorgestrel (IUD-LNg), and distribution of mosquito repellent for pregnant women.

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### **For pregnant women infected with the Zika virus and in mental distress due to the epidemic, ADI 5581 demanded:**

- The right to choose to terminate a pregnancy to protect one's mental health, given the understanding that the Zika virus subjects infected women to intense suffering in the face of uncertainty about the effects of the infection on their pregnancy. In addition to the neglect of the Brazilian State in eliminating the vector mosquito, the epidemic creates a need to protect the health of pregnant women tormented by fear of Zika.

## TECHNICAL OPINIONS FOR ADI 5581

**Alberto Silva Franco** (former judge and founder of the Brazilian Institute of Criminal Science - IBCCrim).

Argued that abortion by women infected with the Zika virus did not meet the normative elements in the penal code that typifies abortion as a crime, and therefore should not be criminalized;

**Eva Kittay** (honorary professor of philosophy at Stony Brook University, United States, specialist in ethics and disability studies)

Argued for the need to value the lives of people with disabilities and their caregivers, which should be guaranteed not only through adequate social policies, but also through the guaranteed ability for families to decide if and when they are prepared to care for a child with a disability;

**Fernando Gaiger** (researcher for the Institute of Applied Economic Research, specialist in inequality, poverty, and social protection)

Argued in favor of income assistance policies for families

affected by the epidemic based on the plasticity of the concept of poverty, stating that it is necessary to consider the impacts that disability causes on household income and the consequences of this impact on childcare;

**Researchers and Professors with the Global Health Justice Partnership, Yale University, United States**

Reiterated the responsibility of the State for the impacts and worsening of the Zika epidemic, (mainly due to the lack of public health infrastructure) to contain its advance on the most vulnerable populations, which generated a duty of reparations;

**Ilana Löwy** (senior researcher at the medical and social research center CERMES-3, France, specialist in the history of medicine and biomedical sciences)

Recounted historical events such as rubella infection and the effects of using thalidomide in other countries to argue the need to guarantee the right to abortion when external agents cause congenital changes in

fetuses and mental suffering for women;

**Laura Rodrigues** (professor of Epidemiology of Infectious Diseases at London School of Hygiene and Tropical Medicine, United Kingdom, member of the Microcephaly Epidemic Research Group and international member of the Brazilian Academy of the Sciences)

Recounted the history of the Zika virus in Brazil and what was known thus far about congenital Zika syndrome and complications for fetal development in addition to microcephaly;

**Rebecca J. Cook** (emeritus professor and co-director of the International Program on Reproductive and Sexual Health and Law at the Faculty of Law, University of Toronto, Canada)

Explained the obligations of countries that had been severely impacted by the Zika epidemic under international and regional human rights treaties for the protection of sexual and reproductive health.

## Community Mobilization:

Information Access Workshops Held by Anis in 2018 and 2019 With the Support of The International Planned Parenthood Federation Western Hemisphere Region (IPPFWHR)



For four years, the pending case at the Brazilian Supreme Court provided a basis for maintaining the issue in the media and among the justices, both in terms of the urgency for a ruling and as an impetus for the continuous mobilization of women and communities.



### 10 Brazilian States

Alagoas, Bahia, Ceará, Distrito Federal, Paraíba, Goiás, Pernambuco, Rio de Janeiro, Rio Grande do Norte, Maranhão

Between 2017 and 2020, with the support of IPPFWHR, we held **70 meetings for information access workshops** with more than 800 women and health professionals in **10 Brazilian states**.

The workshops were instrumental in strengthening **community leadership** and raising awareness among health professionals about sexual and reproductive health issues in times of Zika.

Through our engagement with women and families, we were able to **produce informational materials addressing the most common questions and unmet sexual and reproductive health needs, as well as materials about the social benefits to which families were entitled and the rights of women and children with disabilities.**

We also provided technical support for the creation and formalization of community associations of women and families affected by Zika, a fundamental instrument for expanding capacities for local advocacy and community mobilization.

We have kept in contact with the women and community leaders of the associations to

provide support for local administrative and judicial demands.

**The strengthening of local leadership to promote community engagement is a powerful tool for empowering women and girls in the fight for reproductive justice.**

## Women Leaders of Community Associations of Families Affected by Zika



**Rochelle and Hickelly, 2020**

**Rochelle dos Santos is the mother of Hickelly**, who is four-years-old. She is one of the founders of AMIZ-Goiás, a community association in the central Brazilian state of Goiás that was founded in 2019 with technical support from Anis.

**Alessandra dos Santos is the grandmother of Erick**, who is four-years-old. She is the president of the Families of Angels Association of the State of Alagoas, which was founded in 2017 with technical support from Anis.



**Alessandra, 2019**



**Thamires, Wallace and Miguel, 2019**

**Thamires da Silva and Wallace are the parents of Miguel**, who is four-years-old. With support from Anis, they attended the [Women Deliver Conference 2019](#) in Vancouver to share their stories. In 2017, Anis provided technical support for the foundation of Associação Lótus in Rio de Janeiro, of which Thamires and Wallace are a part of.



 **Luciana Boiteux, Luciana Genro, Gabriela Rondon e Sinara Gumieri**  
Advogadas

Quarta-feira, 15 de março de 2017

## **A ADPF 442: ousadia necessária para descriminalizar o aborto**

The debate that was mobilized in regard to the right to abortion created an opportunity for the filing of the **first constitutional case in a Latin American court demanding the decriminalization of abortion up to 12 weeks**, without restrictions. The lawsuit, ADPF 442, was brought in March 2017 by the Socialism and Freedom Party (PSOL), with support from Anis. Before the discussion prompted by the Zika lawsuit, we had not been able to identify any willing partner

organizations to file such a broad lawsuit with the court.<sup>1</sup> Since its filing, ADPF 442 has become the lawsuit that has generated the **greatest mobilization of civil society in the history of the Brazilian Supreme Court** with more than 50 applications for admission as amici curiae, the majority of which are in support of the lawsuit. In 2018, the Court held public hearings on the topic, which were heavily covered by the press, and a ruling in the case is still pending.

1. Only certain legal and recognized entities, such as nationally representative associations, trade unions, and political parties, can file constitutional lawsuits directly to the Brazilian Supreme Court.

Between 2016 and 2020, the Brazilian Supreme Court was scheduled four different times to issue a ruling on ADI 5581. Even when no final court's decision was reached, each time it was placed on the agenda there was a new opportunity for more public discussion about the multiple demands of the suit.

In addition, in 2019, driven by the return of the Zika lawsuit to the Supreme Court's agenda for the third time, parliamentarians, with support from Anis, presented legislative bills aimed at expanding access to income transfer benefits for families affected by Zika.



**Rochelle dos Santos and her daughter Hickelly** in a private hearing with the Supreme Court Justice Cármen Lucia, scheduled by Anis.



In 2019, with Anis' support, federal congresswomen **Natália Bonavides** presented a bill to facilitate access to the cash transfer benefit (BPC) for families affected by Zika.

While they had previously only mobilized against Zika-related demands, specifically to attack the possibility of decriminalizing abortion, the conservative sectors, including the base of Jair Bolsonaro's government, were compelled to at least concede on the proposal to institute a **lifetime pension for victims of Zika**. The pension law went into effect in early 2020. Although the final law did not incorporate ideal wording, it does provide **yet another remedy for women and families affected by Zika, and is particularly crucial given the exacerbation of inequality and poverty that may impact these communities as a result of the COVID-19 pandemic**.

In late April 2020, ADI 5581 was placed for the fourth and final time on the Brazilian Supreme Court's agenda, this time for a virtual ruling due to the need for social distancing. With little attention from the public, which was concentrated on the pandemic and political crisis, the case was rejected for procedural reasons, that is, without any analysis of the merits of the demands.

Luis Roberto Barroso, the only justice who decided to comment in his vote on some aspect of the merits, said:

it was long past time for the decriminalization of abortion in Brazil and that Brazilian women should no longer "be wombs in the service of society".

The case was closed but it left its mark in the continued fight for reproductive justice.

PANDEMIA DE CORONAVÍRUS | TRIBUNA

## STF volta a encarar o Zika vírus, uma epidemia que não acabou

Quatro anos depois, em meio à pandemia do novo coronavírus, Supremo julgará no dia 24 de abril o direito ao aborto em caso de sofrimento mental ou assistência social às crianças afetadas pela Zika



DEBORA DINIZ | GISELLE CARINO  
17 ABR 2020 - 16:52 BRT

Column by Debora Diniz and Giselle Carino from IPPFWHR, El País.

**Zika e o direito das crianças**

Sou responsável por uma criança afetada pelo zika. Que direitos ela tem?

**Crianças com a síndrome do zika** (que pode ser microcefalia ou outras dificuldades no desenvolvimento) são pessoas especiais e com deficiência, e **têm DIREITOS IGUAIS** de saúde, educação, transporte e participação social.

Todas as crianças e famílias afetadas pelo zika **têm o direito de não sofrer nenhum preconceito ou discriminação.**

**Quais são os direitos que uma criança afetada pelo zika e sua família têm?**

**DIREITO AO TRANSPORTE GRATUITO** para você e sua criança até o serviço de saúde, se sua casa ficar longe de onde forem as consultas (a mais de 50 km de distância).

O que fazer se a prefeitura da sua cidade disser que não tem dinheiro para lhe garantir o transporte gratuito? Nesse caso, você poderá procurar a defensoria pública da sua cidade. Não esqueça de levar todos os seus documentos e de sua criança.

**DIREITO À SAÚDE** e atendimento especializado, com estimulação precoce para fortalecer o desenvolvimento da criança.

**DIREITO AO BENEFÍCIO DE PRESTAÇÃO CONTINUADA** se sua família passar necessidade. Ele deve ser garantido a pessoas com deficiência de famílias de baixa renda. O BPC tem o valor de um salário mínimo e é pago todo mês.

**ATENÇÃO:** As famílias com crianças afetadas pelo zika têm direito de pedir o BPC diretamente no INSS com o laudo do médico, de forma gratuita. Isso quer dizer que você não precisa pagar um advogado.

**COMO PEDIR O BPC:** você pode fazer um agendamento na **central de atendimento da Previdência Social, no telefone 135.** A ligação é de graça se você ligar de um telefone fixo.

anis | BrazilFoundation

In partnership with IPPFWHR, UN Women and Brazil Foundation, Anis developed information access materials for women who live in the epicenter of the Zika crisis in Brazil. Alliances with local governments and public officials were fundamental for ample distribution of informational pamphlets to women assisted by the public health services.



Marisa and Ester, 2017

## REPRODUCTIVE JUSTICE LESSONS FOR HUMANITARIAN CRISIS RESPONSES

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After almost five years of mobilization around the multiple health and social justice needs exacerbated by the epidemic, it may be possible to say that today the intersectionality of the demands that were at the heart of the Zika crisis are more visible than before. The gains in advocacy are not always linear nor can they be counted only by legal or regulatory changes, but even these were present, such as by the institution of the lifetime pension for children with CZS, or by the vote of the Supreme Court justice who added the urgency of the demand for decriminalization of abortion in the country.

**The formation of new alliances to expand a progressive ecosystem, the strengthening of leadership**

**among women from the communities most affected by the virus, and the qualification of the public debate on sensitive issues are significant and sustainable gains for the continuation of the fight for reproductive justice, social justice and disability justice. In the approaching post-pandemic world, these gains will be instrumental in guaranteeing the rights of women and girls.**

Thus, in the face of a new health emergency, in addition to the persistence of Zika's legacy, **revisiting the lessons learned in Brazil can provide important tools to continue the fight for reproductive justice in Latin America and the Caribbean.**

