

A woman with dark hair, wearing a red and white striped shirt, is looking down at a baby. The background is a blue patterned cloth with red stitching and fruit designs.

UNHEARD VOICES

WOMEN'S EXPERIENCES WITH ZIKA

EL SALVADOR

CENTER
FOR
REPRODUCTIVE
RIGHTS

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T.H. CHAN
SCHOOL OF PUBLIC HEALTH

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Glossary

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Pandemic: An epidemic that spreads globally.

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

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

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

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

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

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

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

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

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

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

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

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

Zika Virus: An arbovirus that typically presents with mild symptoms such as fever, headache, rash, and muscle or joint pain typically 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 their fetus. To date, there is no specific treatment or vaccine currently available for Zika.



Foreword

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

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

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

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



Executive Summary

As of November 2017, El Salvador had over 11,805 confirmed and suspected cases of the Zika virus, with the highest incidence in the departments of Chalatenango, Cuscatlán, and Cabañas, making Central American the region in the world with the third highest concentration of the virus. 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 Zika. While the Pan American Health Organization only reported four cases of Congenital Zika Syndrome in the country, the United Nation's Children Fund (UNICEF) 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.

In January 2016, El Salvador's Ministry of Health advised women to avoid pregnancy for two years. In response to similar warnings in Colombia and Brazil, in February 2016, the World Health Organization (WHO) came out with a public statement declaring the Zika epidemic a Public Health Emergency of International Concern. The WHO and U.S. Centers for Disease Control followed this announcement by advising pregnant women against traveling to the more than 45 countries where Zika was present, getting tested if they had traveled to those regions, and refraining from unprotected sex with partners who had visited these areas. Despite these initial broad preventive measures, as of March 2017, over 70 countries and territories had reported evidence of mosquito-borne Zika transmission.

By 2017, as the number of cases of Zika decreased considerably in El Salvador, as well as other countries in Central America, the WHO declared an end to the emergency status. However, some public health experts worried that losing this "international emergency" status would deprioritize states' efforts to effectively and efficiently respond to the epidemic. In response to this concern, Dr. Peter Salama, executive director of the WHO's Health Emergencies Program, 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." Nevertheless, despite the WHO's clarification, that was not how the message was interpreted by governments in Zika-affected countries.

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 governments 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), advising women to avoid pregnancy was not a realistic strategy. This approach did not adequately integrate a human rights-based approach and thus did little to ameliorate the complications that resulted from the Zika epidemic.

What are the consequences of Zika?

Zika is primarily spread by an infected *Aedes* species mosquito; it can also be sexually transmitted or passed from a pregnant woman to her fetus. A fetus infected with Zika can develop prenatal complications, such as microcephaly and/or Congenital Zika Syndrome (CZS). To date, there is no vaccine or medicine available to prevent or treat Zika, and diagnostic testing tools remain inconsistently implemented throughout the region.



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 seizures in their muscles or joints, preventing them from moving and maintaining balance; they may also experience developmental delays, vision and hearing alterations, and clubfeet. These complications can range from mild to severe, and can even be life threatening. Because it is difficult to predict at birth what problems a baby may have 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 life. Unfortunately, to date, there is no known cure or standard treatment for complications related to microcephaly or CZS.

Many public health experts interviewed for this report criticized El Salvador's government for the prioritization of vector control as a means of managing the spread of Zika. This focus on vector control 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 the Global North were advised not to travel to Latin American countries that had reported cases of Zika, impoverished women living in infected areas in El Salvador were simply instructed to avoid getting pregnant. These warnings however, were not accompanied by adequate health care information or services that would allow 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.

Our Findings

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. Additionally, shortly after the WHO declared the global health emergency, the importance of sexual and reproductive rights in the global response to Zika was affirmed by the United Nations Population Fund (UNFPA), the Office of the United Nations High Commissioner on Human Rights (OHCHR), and the Inter-American Commission on Human Rights. Despite this affirmation, 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, 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.



Contraception and Information Access

Family planning was a critical challenge in responding to the threats posed by Zika. In El Salvador, the highly conservative 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 is required for medical procedures for women under 18 years of age, 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. Although the U.N. Committee on the Rights of the Child and the WHO 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. 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.

During the interviews we conducted, we found that none of the five pregnant women we spoke with in San Salvador had been consistently using contraception before becoming pregnant during the Zika epidemic, and that their reasons for not doing so—misconceptions about the risks or side effects—reflected a lack of education about contraception or support from health care providers.

Abortion Access

El Salvador’s has one of the most punitive abortion laws in the world. Not only is abortion illegal in all cases—even to save a woman’s life—in practice it can carry a prison sentence of up to 50 years as most women who are discovered to have had abortions are prosecuted for murder. Further, 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 a patient’s confidentiality, which has been interpreted to include abortion.

The result is that many women who suffer serious, unprovoked complications in pregnancy, such as a miscarriage, opt not to seek health care assistance due to a fear 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. In a highly conservative country like El Salvador, there is also strong stigma against speaking about abortion law reform and reproductive rights. Those who do speak out are often subject to abuse, aggression, political violence, and harassment.

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 which criminalizes abortion, 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 legislative assembly to comply with its international human rights obligations and legalize abortion.

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.

The Rights of Children with Disabilities

Despite the low number of reported cases of children born with disabilities, we found that social inclusion and access to support mechanisms were some of the largest concerns of families with children with disabilities—particularly for women living outside the capital. These families were typically among the most socioeconomically vulnerable, making the added responsibility of taking care of a child with special needs all the more difficult. Without universal health coverage and integrated social welfare support systems in place, we found that children with disabilities, and their caretakers—the majority of whom were women—were particularly vulnerable.

Despite the fact that officials from both UNFPA and UNICEF said the country's experience with Zika had prompted the government to reflect and improve on its treatment of people with disabilities, thus far, we have found no new programs in El Salvador that specifically support children born with Zika-related health complications.

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

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

During on-site visits in San Salvador, we saw untreated open sewage and storm drains, creating unsanitary standing water conditions near the communities we directly interviewed. These areas were said to have poor access to water and sanitation and are situated in a swamp that makes control of mosquitos particularly difficult. Our research found that the lack of investment in water and sanitation infrastructure by the government contributed to the conditions that increased the proliferation of mosquitos, quickening the spread of Zika.

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 upon families and caregivers of children with disabilities



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

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

El Salvador is a state party with a number of international human rights instruments that protect women's fundamental rights, the rights of people with disabilities, the right to water and sanitation, and the right to the highest attainable standard of health, among other socioeconomic rights. Under international human rights law, countries are required to prioritize women's autonomy and self-determination by ensuring their right to comprehensive reproductive health information and services. El Salvador also has an obligation to provide the support, training, and services necessary for raising a child with a disability. As established in the El Salvador Constitution, international treaties ratified by the state constitute laws of the country, and in the case of a conflict between a treaty and a national law, the treaty prevails. Therefore, as a signatory of these international and regional instruments, El Salvador must work to respect, protect, and fulfill these human rights.

Conclusion

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

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

Although there remains the possibility that positive law and policy changes could emerge as the government and their citizens reflect on the Zika epidemic and its impact, this seems increasingly unlikely given that the stories detailed in this report highlight the limited extent that women's perspectives were taken into consideration during the outbreak. Through their testimonies, it has become apparent that El Salvador's government 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, which further exacerbated existing inequalities.



Methodology

In March 2017, we held focus group interviews with five women aged 22 to 32 years old in San Salvador, the capital and largest city in El Salvador. Interviewees included four women who were diagnosed with Zika while pregnant and one woman who was suspected of having Zika while pregnant, but was subsequently diagnosed with dengue.

San Salvador was selected as the study site because it is one of the cities that has been most affected by Zika. Due to security concerns, including a strong gang presence in Zika-affected areas, our researchers were unable to travel to more rural regions. In respect to sampling, we were assisted by El Salvador's Ministry of Health who brought women to a secure location for interviews. This meant that the interviewees were women who were more connected to the health care system as opposed to those who lacked access.

Interviews were also conducted in March 2017 with 15 key stakeholders in the fields of health care and government as well as from international and civil society organizations in San Salvador. Interviewees included four participants from the national government at the Ministry of Health, four members of the legislative assembly, three individuals working in the health care sector at the National Health Institute and *Hospital de la Mujer* (Women's Hospital), # private practice doctors, two employees from the United Nations Children's Fund, and the United Nations Population Fund, and two staff members from *Agrupación Ciudadana*, a local civil society organization. In our interviews, we collected data on the conditions facing women in other parts of El Salvador, particularly those lacking access to the health care system, to reflect different experiences than those captured solely by the women interviewed in San Salvador.

Researchers complied with the Lund-London Guidelines on fact-finding reports by non-governmental organizations and completed the Protecting Human Research Participants training program offered by the U.S. National Institutes of Health's Office of Extramural Research. Informed consent was obtained from each interviewee and all data and information was securely recorded and stored. Any interview information collected by the Yale Global Health Justice Partnership for this report was gathered pursuant to IRB approval from Yale University.



Background

El Salvador has a population of 6.1 million with a density of nearly 306 persons per square kilometer as of 2016. The country is predominately Christian: 47% of the population identifies as Roman Catholic and 33% as Evangelical. While the Constitution of El Salvador recognizes freedom of religion and equality before the law without religious distinction, it also affords special recognition to the Catholic Church, which retains significant political power that has been used to restrict women's reproductive rights. Additionally, the Constitution does not explicitly establish a secular government.

The population of El Salvador has become increasingly urbanized in recent decades: 67% of residents currently live in urban areas. Although poverty is widespread—approximately 32% of the population is living below the national poverty line—poverty is particularly high in rural areas where approximately 38% of the population lives in poverty.

Much of the violence in El Salvador is driven by powerful gangs and drug-smuggling networks as well as the government's often heavy-handed efforts meant to quell these groups. Until a truce was facilitated between competing gangs in 2012, the country had one of the highest rates of homicide in the world, with extortion and threats noted as widespread forms of violence. Gangs use threats and violence to impose an extreme degree of control over the population, including curtailing peoples' freedom of movement. Violence has also led to significant population displacement within El Salvador. A recent survey found that in 2014 alone nearly 300,000 of the country's residents—a number equal to the entire population of San Salvador—were displaced by criminal violence and threats. In terms of associated health implications, public and private health professionals have reported difficulty in accessing and providing services in gang-controlled areas.

As with many other infectious diseases, the spread and impact of Zika is tied to social and economic inequalities. Zika has most affected low-income women, reflecting broad inequities in areas such as water and sanitation infrastructure and health care. Strict abortion restrictions coupled with laws that restrict sexual education and access to contraception for adolescents have compounded the disproportionate consequences of Zika on women in El Salvador. These restrictions have limited the ability of the health system to adequately respond to the Zika public health crisis and have prevented individuals from making informed and autonomous decisions about their health.

Women and girls in El Salvador have lower education levels, higher school dropout rates, and nearly double the illiteracy rate of their male counterparts. Salvadoran women also have lower participation in the formal workforce and lower incomes. These gender disparities are even starker for certain women and girls, including those who are pregnant, poor, and/or Indigenous. These are also the same women and girls who are most vulnerable to Zika and its long-term impact.

El Salvador also has a deeply rooted sexist culture, which manifests itself in various aspects of women's lives and intimate relationships, including high levels of violence. One survey found that almost half of Salvadoran women who had been in a relationship reported experiencing violence at the hands of their partner. The number of rapes in the country has also appeared to be increasing in an environment where

few services are available to victims and most incidences go unreported. Intimate partner violence has significant effects on women's reproductive health, especially when the violence is directly related to reproductive health (e.g., forcing an individual to use or not use contraceptives, forcing or coercing an individual to have or not have an abortion) or indirect (e.g., injuring an individual physically or mentally to prevent them from exercising their full reproductive freedom).

Zika Outbreak and Response

Zika was first reported in El Salvador in November 2015 and peaked in January 2016 with 1,144 cases reported per week. By 2017, the number of cases had fallen considerably; while 6,553 cases had been reported in 2016, only 182 cases were reported between January 1 and May 20, 2017. Despite this decrease, the total incidence of Zika is still the third highest in Central America. Over the course of the outbreak, Zika spread to all of El Salvador's fourteen administrative departments, but the highest incidence has generally been in Chalatenango, Cuscatlán, and Cabañas.

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 virus. The first case of Zika-associated microcephaly was reported in June 2016; by April 2017 there were four confirmed cases. However, according to the most recent available reports by the Pan American Health Organization, El Salvador has 72 suspected cases of microcephaly under investigation.

In January 2016, El Salvador's Ministry of Health advised women to avoid pregnancy for two years in light of the Zika epidemic. Many criticized the government for issuing this advice, noting that women in El Salvador lack control over their reproductive health. Simply telling women to avoid becoming pregnant was not a realistic strategy that would yield effective results. The impact gender inequality has on preventing women from exercising reproductive choice has been well documented in El Salvador where the inequalities are particularly salient among young women and girls. In fact, El Salvador has the highest rate of teenage pregnancy in Latin America: One third of Salvadoran babies are born to girls and women under the age of 19. While 73% of all women of reproductive age report using some form of contraception, research has found that only 38% of sexually active adolescent girls are using contraception regularly.



A woman with dark hair, wearing a blue and white striped short-sleeved shirt, is holding a baby. The baby is wearing a pink long-sleeved shirt. They are lying on a blue blanket with a colorful pattern of red stitching, green leaves, and red apples. The woman is looking down at the baby with a gentle expression.

PATRICIA'S STORY: PREGNANT WITH ZIKA

Patricia is a 27-year-old homemaker living in San Salvador. She is married and recently had her third child who was born after she had been diagnosed with Zika while pregnant.

Image is not of Patricia and is solely representational.

During her pregnancy, Patricia first learned that Zika was transmitted by the same mosquito that transmits dengue and chikungunya, has symptoms like a rash and fever, and could cause problems with pregnancy. “The [Zika] campaign was pretty intense here in the country,” she noted of the information provided by the government and media on the epidemic. Patricia also shared that she felt fear had grown in El Salvador after seeing so many cases of microcephaly emerging in Brazil. To combat the outbreak, she heard recommendations such as using mosquito nets, wearing insect repellent, and disinfecting water sources.

Still, Patricia did not feel that she had all the information she would have needed *before* becoming pregnant to be able to protect herself. “If I had known before, I would have done everything possible to take care of myself.” However, she suggested that it may have been too early in the epidemic for women to have had all the information they needed to make educated decisions about their reproductive health.

While she had not planned on becoming pregnant at the time, Patricia had recently stopped using birth control because she believed both oral and injectable contraception had been giving her headaches. While she said that she frequently saw community health workers in public areas sharing information about contraceptive methods, given her side effects she felt the best thing to do was to stop taking them altogether. That is when she became pregnant, which happened to be in the midst of the Zika epidemic.

When she was four months pregnant at a regular prenatal checkup, her doctor noticed that her eyes looked bloodshot and that she had a rash on her stomach and back. They referred her to another doctor who sent her to a nearby hospital where a Zika infection was confirmed with a blood test. She was then told that the remainder of her prenatal care and delivery would happen at a hospital, rather than at a smaller health care center. From that point on, she had an ultrasound each month and the size of the fetus was monitored for potential signs of microcephaly.

Unlike with her first two pregnancies, this time Patricia said she was in constant fear of what could go wrong. “I would wake up at dawn, my hands tight with the nervousness I felt,” Patricia explained. Many nights she dreamed of the complications she could encounter this time around.

Although Patricia had been told that her baby would immediately be seen at a children’s hospital after birth for additional tests, she was not referred anywhere after she delivered. Six months later, when a doctor discovered that her baby’s head was an unusually large circumference, she was finally referred to a specialty hospital. While they ran many tests, they did not discover any problems—her baby’s head was simply little larger than the norm. As of today, her baby has had no sign of health complications, and her own Zika infection seems to be behind her.

The Right to the Highest Attainable Standard of Health

The right to health is a fundamental right indispensable for the enjoyment of other rights that is enshrined in many international human rights instruments. 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 affirms: “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, states parties recognize “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”

The U.N. Committee on Economic, Social, and Cultural Rights developed the content of the right to the highest attainable standard of health in its General Comment No. 14, 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.”

Testing and Surveillance

As of November 2017, El Salvador had reported over 11,805 cumulative cases of Zika. When the World Health Organization first issued an alert about Zika in the Americas in May 2015, El Salvador’s Ministry of Health issued their own alert and began integrating surveillance of the disease into its overall surveillance system. El Salvador was one of the first four countries to confirm the presence of Zika in November 2015, which its Ministry of Health said, “indicates the strength of the health surveillance system” the country had in place. A health promotion official with the Ministry of Health said that they attempted to build off their experience with other arboviruses, such as dengue and chikungunya, in their response to Zika rather than starting from scratch. The weekly epidemiological bulletin called for “surveillance of congenital abnormalities...with the aim of detecting some unusual increase” and noted that “it is important to ensure assistance for pregnant women and monitoring.” While the Pan American Health Organization (PAHO) only reported four cases of a congenital syndrome associated with Zika in El Salvador, an expert at the United Nations Children’s Fund (UNICEF) reported that a comparison of pre- and post-epidemic rates of microcephaly indicated the number of Zika-related cases may be much higher.

The Ministry of Health claimed in June 2016 that 100% of the pregnant women who had been identified as likely having been infected with Zika were receiving follow-up care, and a representative from PAHO said that the monitoring of pregnant women was “adequate.” However, given that members of the Ministry of Health said in interviews that the health system lacked an equal presence in parts of the country that were particularly impacted by gangs and violence, it is very unlikely that all pregnant women with Zika were identified, and thus there were infected women who were not being monitored. The Ministry of Health



issued specific guidelines for the monitoring of babies born with Congenital Zika Syndrome as well as those born with no complications but who were at risk of developing Zika-related complications as they developed, recommending that they be referred to community providers for follow-up care several times a year.

Several problems were identified in El Salvador with respect to resources needed to properly implement a successful surveillance system. Interviewees from UNICEF and the United Nations Population Fund (UNFPA) both noted that Zika infections were often asymptomatic, and the National Institute of Health (*Instituto Nacional de Salud*, INS) added that even people with mild symptoms may not have sought out care and therefore had not been recorded in the system or given follow-up care. Additionally, an INS official pointed out that Zika symptoms could easily be confused by infected individuals—and even health care professionals—for other arboviruses. The INS admitted that many doctors were hardly trained on dealing with Zika, so even when it might have been possible to give a clear diagnosis, several may have failed to do so.

The United States Agency for International Development reported that early in the epidemic, El Salvador was sending samples to a Centers for Disease Control and Prevention facility in the United States because it lacked the ability to conduct testing on its own. Once Ministry of Health staff were trained, they began to confirm cases locally, but continued to report “having a very minimal supply of the reagents needed for the laboratory test and felt this limited their ability to carry out wider testing.” In fact, personnel with the INS interviewed for this report confirmed that the government lacked the capacity to test all the samples that arrived during the height of the Zika epidemic, and that priority was given to pregnant women and children because not all of the samples could be processed. A UNFPA representative also explained that some facilities, especially basic community centers, referred patients to higher level facilities that could appropriately take and send samples for testing, yet patients didn’t always follow up with the referral and thus the sample would get lost in the system. Finally, our INS interviewee said that even when cases could be identified, not all facilities were able to report them because some health care centers lacked internet access or the computers needed to participate in the digital surveillance system.

One doctor explained that a major challenge in managing the Zika epidemic was the “lack of human resources knowledgeable in the management [of the disease].” She also noted that “inputs from the laboratory” to confirm diagnoses and the need for “a psychologist to accompany a person” through the

difficult time of being diagnosed complicated matters. Although a UNFPA representative said that the government had significantly increased ultrasound use in prenatal care in response to Zika, the doctor we interviewed felt otherwise. She explained that the lack of basic equipment and supplies to provide maternity care to the population has had an incredibly harmful effect on pregnant women in light of the epidemic: “How I wish I could have ultrasound machines in every single hospital and have the person who does the ultrasounds,” she said.

In addition to limitations in human and physical resources, women also faced many cultural and socioeconomic barriers when seeking the Zika testing and care they needed. For example, while the asymptomatic nature of a Zika infection was problematic in all countries responding to the epidemic, the fact that nearly half of El Salvador’s population reported never getting care for their last illness signals a culture where individuals often go without treatment, a problem that was further exacerbated in regard to Zika. Additionally, a UNFPA official reported that there was no protocol in place to actively seek out pregnant women and help them get the required testing, monitoring, and care needed to manage the virus. Instead, government efforts were contingent on women getting care on their own. The UNFPA official we spoke with also noted violence as a barrier women faced in getting treatment, sharing that many women who may have believed they were infected, and were in close proximity to a clinic, may not have been able to get care due to the high prevalence of violence plaguing the country.

The country’s extreme abortion ban has also had a chilling effect on women’s ability to access reproductive health care, a problem that speaks to the pervasiveness of structural violence in El Salvador. As an INS official pointed out, rooted sexism and limited socioeconomic opportunities presented barriers for women as many could not even afford the transportation costs required to seek health care; women also faced a cultural barrier in that “women depend on men when it comes to deciding if they are going to consult a doctor.”

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 reproductive health information and education. For women to be able to make informed decisions about their reproductive lives, states must ensure that all women have access to both comprehensive sexual and reproductive health services and information. The disseminated information must be accurate, unbiased, and evidence-based so women can make informed decisions about pregnancy and parenting.

Information must also be disseminated in a timely and inclusive manner. 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. States must also ensure that women and their communities are aware of how Zika is transmitted and what preventative measures are available to mitigate the spread of this virus.

Zika Prevention

The spread of Zika can be controlled in three ways: (1) eliminating the mosquitos that carry it, (2) preventing individual infections by encouraging actions like using insect repellent, and (3) preventing sexual transmission by promoting and facilitating safer sex. Of these three activities, the focus of the government of El Salvador—like most governments dealing with the epidemic—was on vector control of the mosquito itself. As such, the Ministry of Health integrated a vector control strategy using their existing plan for managing other arboviruses reasoning that the same mosquito spreads other diseases like chikungunya and dengue. Their national strategy came together at a countrywide meeting during the epidemic, and centered on the use of community health workers and entomologists to identify the *Aedes aegypti* that carries these kinds of arboviruses and eliminate them.

The Chief of Health Promotion at the Ministry of Health said that another major strategy for the prevention of Zika was educating the public about avoiding areas where mosquitos breed. This was largely done via radio, social media, print media, and television. The information shared also included messages specifically targeted at women on Zika's symptoms and instructions for seeking care. Community health workers shared this same kind of messaging in the regions where they were working at the grassroots level. However, the Chief of Health Promotion noted that messaging aimed exclusively at women was problematic. He said, "it is an inequity that after working the whole day at the textile factory or at the market selling her products we say to a woman, 'Okay, after all that, go home [and] wash your water tank with bleach.'" Instead, he recommended that the Ministry of Health convey that these kinds of prevention strategies are incumbent on all people—not just women.

A major shortcoming of El Salvador's informational campaign was its emphasis on vector control. The strategy should have also focused on preventing the sexual transmission of the virus. Representatives from the Ministry of Health confirmed that many doctors did not prioritize informing patients about the sexual transmission of Zika because they did not think that it was a common occurrence. Indeed, one physician interviewed stated that he normally did not focus his prevention message to patients on sexual transmission because he himself did not know much about it and did not believe it happened frequently. Additionally, it was found that while 31% of Salvadorans were using mosquito nets during the epidemic, only 5% were using condoms. None of the five low-income, at-risk women interviewed knew that Zika was transmitted sexually, even though they all lived in the capital and were connected to the health care system; only one woman who had contracted Zika, a professional working for a women's rights nonprofit, was aware of the ability to get Zika through sexual transmission.

The omission of sexual transmission in El Salvador's informational campaign combined with the public's low awareness of this concern can be seen, in part, as a shortcoming of the government's strategy to incorporate Zika into its existing efforts to address other arboviruses that are not generally transmitted sexually. As a result of linking these diseases together, the public never came to understand this key difference—that Zika can be transmitted sexually. Although the sexual transmission of Zika was first documented in 2008, reports of Zika being sexually transmitted continued to be rare until the World Health Organization confirmed this information in 2016 and advised governments to warn people even though the exact risks were still unknown.

The failure to educate the public and health professionals about the sexual transmission of Zika must be seen within the greater context of the government's widespread violation of women's sexual and reproductive rights, including access to science-based information. In a region where women have limited

access to sexual education and contraception, no access to legal and safe abortion, and face widespread gender-based stereotypes and marginalization, knowledge about Zika's sexual transmission and access to condoms are all the more important.

Despite the government's failure of educating people on the sexual transmission of Zika, the Ministry of Health said they promoted and encouraged other means of protecting oneself from the virus, including using bleach to kill mosquitos in breeding areas, wearing long clothes, and using insect repellent. The United Nations Population Fund supported the government in distributing insect repellent at least once during the epidemic, and said that hospitals generally had bed nets and repellent, especially for pregnant women. While prioritizing pregnant women was a good starting point, the opportunity to target women who may become pregnant in the future was missed. In order for prophylactic measures to succeed, women need to be targeted before they become pregnant.

States Prevention and Treatment Obligations

According to Article 12(c) of the International Covenant on Economic, Social, and Cultural Rights, state parties have an obligation to take every measure required for the prevention, treatment, and control of epidemics. General Comment N°1 of the U.N. Committee on Economic, Social, and Cultural Rights mandates that states are obliged to establish “prevention and education programs for behavior-related health concerns,” particularly those that adversely impact an individual's sexual and reproductive health. 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.

According to the U.N. Committee on Economic, Social, and Cultural Rights, states are also required to put systems in place for urgent medical care in cases of epidemics or health hazards. This could be achieved through national governmental efforts or collaboration between governments and private entities. Ultimately, the goal is three-fold: (1) ensure epidemiological surveillance and data is used and improved, (2) secure widespread use of all relevant technologies, and (3) implement or enhance disease control strategies. This report has illustrated that there is a need for greater epidemiological surveillance of Zika, particularly in marginalized and remote communities. Additionally, given that a vaccine to prevent the transmission of Zika does not exist other preventative strategies, such as the enhancement of vector control management, the use of insect repellent, improvements to water and sanitation infrastructure and sexual transmission awareness, are even more prevalent.

In the context of Zika, this primarily takes the form of better access to Zika testing, medical abortion pills, and ultrasounds. To ensure that this right is upheld, governments can remove barriers by changing medical protocols or facilitating the approval of new testing technologies.

Family Planning and Contraception

Like several other countries experiencing a Zika outbreak, the government of El Salvador suggested in early 2016 that women consider postponing pregnancy for two years while the epidemic subsided. The Ministry of Health said that an increase in demand for contraceptives, especially implants, was observed following the outbreak and the government's advice to postpone pregnancy. One study suggested that the unmet need for family planning, which could have been satisfied by the provision of modern contraceptive methods, was less than 12% in El Salvador. The Ministry of Health reported that they attempted to meet this increased demand by securing emergency governmental funds to increase supplies of all forms of contraception, including female condoms, to help prevent the sexual transmission of Zika.

The United Nations Population Fund confirmed that an official order was issued to increase funding for the public sector's supply of contraceptives, but noted that such government processes are slow. However, with support from UNFPA, the Ministry of Health was working to permanently make available some of the contraceptives that increased in use during the Zika outbreak response.

Still, expanded supplies and information in light of the Zika epidemic must be viewed within the difficult circumstances women seeking to avoid pregnancy in El Salvador were facing. First, the nation's public education system lacked a sexual health curriculum, and an attempt to incorporate one in 2008 was blocked by the Catholic church. As a result, information available to youth, which largely determines whether they have the necessary information in adulthood, varied greatly by school, said a representative from the women's rights organization *Agrupación Ciudadana*.

In addition to a lack of information, gendered stereotypes in El Salvador often put family planning in the hands of women and girls. A report by the World Bank Group on sexual and reproductive health among adolescents in El Salvador indicated that 25.5% of adolescent girls thought it was the woman's responsibility to prevent unplanned pregnancies versus 12.9% of boys. Moreover, boys were less likely than girls to even know how to prevent pregnancy. This phenomenon was affirmed by an interviewee infected with Zika who said, "the message is totally communicated to the young women—not to men—and so that becomes seen as the women's responsibility. As a result, men are not going to take responsibility." Even for young women who receive education on contraception, this knowledge might not translate into contraceptive use. Research has indicated that in El Salvador, four out of five female adolescents have received information on sexual and reproductive health, including contraception use, but only 18% have reported using contraceptives during their first sexual encounter.

The highly religious culture in El Salvador has also hindered access to contraception. Our research found that health care professionals often denied patients contraception due to their own religious beliefs and that women were often apprehensive about seeking out contraception given the negative stereotypes associated with its use. An emergency and pediatric physician explained, "women think that if they ask you about contraception, they will be seen as sex workers," noting that it is commonly believed in rural areas that most women who use contraception are engaged in sex work. The physician added that it is these types of beliefs that cause women to avoid using contraception even if they know it would benefit them; she said women are dissuaded "out of fear of religion and what people would say about them."

In regard to health care professionals conscientiously objecting to prescribing contraception on religious grounds, one physician noted that many doctors impose their personal beliefs on their patients. The physician said, "is not standardized" but rather "depends on physicians' values" whether or not they claim a religious objection to contraception. Pharmacies, too, have proven to be a source of misinformation and stigma, said a

representative from a women's rights nonprofit who showed fliers provided by a pharmacy dissuading women from using emergency contraception or condoms when customers sought out such services; women who asked for condoms, for example, were instead given a flier which read, "The only solution is fidelity to your partner for your entire life." It was obvious that women were being denied access to contraception by health care professionals and pharmacists who served as de facto gatekeepers to the provision of comprehensive sexual and reproductive health care. This scenario was even more complicated "for those [women] who were unmarried, had fewer economic resources or lower educational attainment and those living in rural areas."

If under the age of 18, parental consent may be required for medical procedures, which also proved to hinder access to contraception among adolescents. 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 Salvadoran Penal Code to mean that they could be criminalized for prescribing contraception. It is out of fear of being criminalized for promoting or facilitating sexual activities among people under the age of 18 that health care professionals often fall back on parental consent. 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 the law has broadened health care professionals' discretion in the provision of contraception. The government must strongly consider the impact of this ambiguity, most notably on the rate of pregnancy among adolescent mothers at risk of Zika-related complications.

None of the five pregnant women interviewed in San Salvador had been consistently using contraception before becoming pregnant during the Zika epidemic. Their reasons for not doing so, including misconceptions about the risks or side effects, reflect a lack of education about contraception or support from health care providers. One woman shared that she was purposely not using contraception because she wanted to become pregnant. Of the other four interviewed women, one had been using contraceptives inconsistently and was pregnant and the other three had all mentioned concerns about contraceptives that had prevented them from using them. In addition to concerns about the safety and efficacy of contraceptives, two of the women we spoke to mentioned that they had stopped using oral and injectable contraceptives after experiencing headaches and other symptoms. While contraception can cause headaches and/or migraines for some women, health care professionals have other contraceptive options available to offer patients to help mitigate this side effect. Interestingly, one woman who had stopped using contraception because of the headaches she was experiencing, and who subsequently had an unplanned pregnancy during the Zika epidemic, reported that she felt that the health care system had served her sufficiently in accessing contraception. This view suggests that women may have low expectations of what the health care system should be providing them with respect to their reproductive health care.

Perhaps relatedly, three of the women interviewed said that in their opinion contraception was a matter of personal responsibility. If a woman became pregnant without intending to be, they said that it was her fault alone. This perspective that the health care system has no responsibility to women, and that those with unplanned pregnancies should exclusively receive the blame, is reflective of the broad stigmatization around contraception and reproductive health in El Salvador. Indeed, four out of five women noted the stigmatization of contraception use as being a barrier. In fact, one woman shared that many people she knows are too "embarrassed" to seek out contraceptives and another said, "some people are too embarrassed to say, 'Look, I want condoms.'"

All five women we interviewed had infections discovered during pregnancy that were suspected to be Zika. One woman was diagnosed without a lab test; one woman was tested but confirmed to have dengue instead;



and the other three were tested and confirmed to have Zika. In each case, the women had not specifically sought out care because of the infection, but rather had seen their doctors for a general prenatal checkup when medical personnel suspected them of having Zika. Notably, all of the women who participated in the focus groups were in regular treatment for Zika within the health care system, a fact that is not true for many infected women in El Salvador, particularly those living in zones with high conflict; it is unclear if any of these women would have discovered their infection had they not already been receiving prenatal care.

After their initial diagnosis, most women reported receiving at least one ultrasound to monitor the health of their fetus; only one woman said she did not receive an ultrasound or any other follow-up care during the rest of her pregnancy. The rest of the women all said they had received at least some degree of follow-up care, although it was unclear if Zika-specific monitoring was being conducted, particularly after the initial determination that their baby was born without any complications. Although three of the women said that they were satisfied with the level of care they had received from the health care system, all five women expressed significant fear after their diagnosis, which for some lasted the duration of their pregnancy. While such fears and anxiety could have been assuaged with mental health support such as counseling, none was offered to the women we spoke with who instead were left to hope for the best on their own as their pregnancies progressed.




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. 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.

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

Contraception Access

Both the U.N. Committee on Economic, Social, and Cultural Rights and CEDAW explicitly recognize that the right to reproductive health must include the availability of contraceptive information and services. 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. Requirements of third-party consent for access to contraception must be removed as international human rights bodies have consistently considered such requirements contrary to women's rights.



In El Salvador, the criminalization of abortion has created a culture in which women who suffer pregnancy-related complications can be sentenced to up to 50 years in prison. Alba Lorena Rodríguez Santos, 30, was raped, became pregnant and suffered an obstetric emergency. She was later sentenced to 30 years in prison for aggravated homicide.



Abortion Access

In our research, women in El Salvador who wanted to terminate a pregnancy due to risks posed by Zika faced some of the most invasive and dangerous restrictions on women's reproductive health found anywhere in the world. Not only is abortion illegal in all cases—even to save a woman's life—but it can also carry a harsh prison sentence of up to 50 years because most women end up being prosecuted for murder. Moreover, the discriminatory and punitive nature of the blanket abortion ban has created a culture in which even women who suffer miscarriages or pregnancy-related complications are often considered suspects for clandestine abortions; these “suspicious” women overwhelmingly tend to be from low-income backgrounds and are often arrested and tried with no concrete evidence or adequate legal representation.

El Salvador's extreme ban on abortion not only impacts women, but the medical community as well. For example, a doctor we interviewed noted that the prosecution of medical personnel who have not reported suspected cases of abortions has created a culture of fear. As a result, many medical professionals feel they must report anyone who seeks care and has medical conditions that could be considered consistent with ending a pregnancy. The doctor we spoke with said that many of his fellow physicians “don't know anything about the law...so if one of their supervisors tells them that they have an obligation to report a case” they do it—even if they suspect a woman had actually suffered a miscarriage. “If they don't do it,” he said, they are made to feel like “they will become accomplices” and many “fear losing their jobs.” The doctor added that many physicians “are not familiar with a patient's right to confidentiality” and that while many may be aware of their responsibilities to their patients, they are fearful of existing laws designed to restrict the rights of their patients to safely access health care.

Researchers also interviewed a physician providing abortion services to individuals in need despite the country's extreme ban. The physician explained that his primary means of getting referrals was through word of mouth, demonstrating that the illegality of the procedure was not stopping women for seeking information on how to access it. The danger, however, was that access to information and abortion services was happening outside of the official health care system, creating health and safety risks for vulnerable women. The physician we spoke with shared a story about a patient he helped who feared she had contracted Zika and her pregnancy may be at risk; due to her concerns, she requested a therapeutic abortion to end the pregnancy. While she never received a confirmed Zika diagnosis, she had also not been able to confirm that she did not have Zika. The difficulty of diagnosing Zika-related complications during prenatal ultrasounds, or even at birth, further complicates the situation. Regardless, the woman did not feel comfortable continuing with her pregnancy and sought out the doctor's services.



The doctor reported that his fees ranged from USD 500-3,000 per surgical abortion procedure, putting the service out of reach for many women in a country where the minimum wage is as low as USD 200 per month. However, he shared that some physicians provide the procedure for a lower price for women without resources or who have a life-threatening emergency. He added that women were also able to get non-surgical, medication-induced abortions on the clandestine market for USD 150-200, which could still represent a cost of up to a full month's salary for a minimum wage worker. Additionally, getting an abortion from someone who is not a medical provider, and does not have a fully equipped and staffed clinic (like the doctor interviewed for this report), can be especially dangerous for women seeking abortions.

Currently, there are several legal challenges to El Salvador's extreme abortion ban that may help expand reproductive rights in the future. Between 2016 and 2017, two bills to partially decriminalize abortion in some cases were introduced and are currently under consideration by the Legislative Assembly, with strong support from civil society and the international community.

In March 2017, the U.N. Committee on the Elimination of all Forms of Discrimination against Women (CEDAW) asked for a review of Article 133 of the Salvadoran Penal Code and called "to legalize abortion at least in cases of rape, incest, threats to the life and/or health of the pregnant woman, or severe fetal impairment." Furthermore, they requested the introduction of a "moratorium on the enforcement of the current law and review of the detention of women for abortion-related offenses." CEDAW also sought to ensure that the "professional secrecy of all health personnel and confidentiality of patients be guaranteed." These recommendations underscored the severe harm El Salvador's extreme abortion ban was placing not only on women in need of abortion services, but on health care professionals trying to provide sexual and reproductive health care.

In lieu of CEDAW's recommendations, in November 2017, 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. Like CEDAW, his goal was to ensure compliance with due process and fair trial standards and release unjustly imprisoned women. In his statement, the High Commissioner called on the president of El Salvador and the legislative assembly to comply with its international human rights obligations and legalize abortion.

Several U.N. Special Rapporteurs have also voiced their support of these recommendations to the Salvadoran government, noting that this change in the law would bring the country in compliance with its international human rights obligations, including those with respect to health as well as the right to be free from torture and inhuman treatment and from violence against women. Joining the call made by the United Nations, the Inter-American Commission on Human Rights (IACHR) released an official statement in March 2018 urging El Salvador to end the country's total criminalization of abortion.

Several legal cases have been brought against the Salvadoran government before international judicial bodies, such as the IACHR, representing women who have been prosecuted for aggravated murder and imprisoned after being accused of having an abortion; a group of such women are known as Las 17. These women faced consistent violations not only of their reproductive rights, but also of their right to medical privacy and their right to effective representation in court and a fair judicial process.

In February 2015, after serving seven years in prison, Guadalupe—one of Las 17—was successfully released and pardoned after the El Salvador Supreme Court recognized “judicial errors” in her prosecution. In May 2016, Maria Teresa, another Salvadoran women wrongly imprisoned after suffering a miscarriage, was released after a judge ruled that there were violations of due process in her case. Maria Teresa was later granted asylum in Sweden and allowed to reside there with her son to avoid the inhumane treatment she would endure if she returned to her own country. She is now the world’s first abortion refugee case reported to date. In February 2016, another woman named Sonia was similarly pardoned and released, and in March 2018, two other women, Teodora and Maira, were also set free. For Teodora, the El Salvador Supreme Court reopened her case and considered the sentence she received to be excessive and immoral. In Maira’s case, President Salvador Sanchez, commuted her prison sentence through the Ministry of Justice.

Despite these stories, to date more than 20 women who suffered pregnancy complications remain in prison after unjustly being convicted of aggravated homicide—some with sentences of up to 40 years. 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.

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.

The Right to Abortion

Under international human rights law, women have the right to “the highest attainable standard of physical and mental health.” The U.N. Committee 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.” Restricting women’s access to safe and legal abortion, particularly to those whose physical and/or mental health is at risk, jeopardizes many of their internationally protected human rights. In fact, U.N. human rights bodies have recognized the negative consequences of restrictive abortion laws on women’s health and have consistently raised concerns about the inaccessibility of safe abortion services. As recognized by the Office of the U.N. High Commissioner for Human Rights: “[e]nsuring access to these services in accordance with human rights standards is part of state obligations to eliminate discrimination against women and to ensure women’s right to health as well as other fundamental human rights.”

Guadalupe Vázquez Aldana, a member of Las 17, was sentenced to 30 years in prison after suffering a miscarriage. Guadalupe and others faced consistent violations not only of their reproductive rights, but of their right to medical privacy, their right to effective representation in court, and a fair judicial process.





Caregiving and Children with Disabilities

It remains largely unknown how many children have been born in El Salvador with Zika-related complications. Partially, this is a result of general shortcomings in the country's testing and monitoring of Zika infections; without knowing how many people have contracted the virus, it cannot be said how many children have been born with related complications. Additionally, some of the same barriers that may have prevented access to testing, monitoring, and care may also have prevented the detection and reporting of microcephaly. What is known is that the first case of Zika-related microcephaly was reported in June 2016 and that as of May 2017 there were only four confirmed cases in the country since the start of the epidemic. Around that same time, however, El Salvador also had 72 suspected, but unconfirmed, cases of microcephaly that were under investigation.

An expert at the United Nation's Children Fund (UNICEF) said that a comparison of suspected microcephaly cases before and after the Zika epidemic that did not look solely at cases currently suspected of being related to Zika suggested that the virus could have had a bigger impact than is currently known. Also, publicly available figures do not include children born with Zika-related complications who were not identified by the health surveillance system. Therefore, the true number of Zika cases in El Salvador is unknown, and it may be impossible to determine at this time given that some Zika-related complications can appear months after birth.

The Ministry of Health issued guidelines for testing babies for microcephaly and other Zika-related complications. They also issued guidelines for monitoring children who appeared to be born without Zika-related complications. The latter was in response to the fact that some children develop complications that are not initially detectable at birth. These guidelines recommended hospitals refer families to the Community Family Health Unit and reiterate the importance of seeking follow-up care from a pediatrician every three months the first year and twice a year thereafter for continued testing and monitoring. However, for families already facing barriers in accessing care, including financial hurdles or fears of seeking care in areas with high levels of violence, a mere recommendation that they seek out follow-up care is unlikely to change the underlying dynamics that shape El Salvador's health inequities.

The Ministry of Health also developed guidelines with the Pan American Health Organization for providing psychosocial support to pregnant women suspected of a Zika infection as well as for those who gave birth to children with congenital malformations. The guidelines instructed providers to "not forget to provide social, human, and psychological care to the family [at the hospital]" and refer them for follow-up care afterward. However, one physician and epidemiologist with a leading maternal health provider noted that many health centers, especially those outside of the main cities, do not have qualified mental health staff. As a result, the guidelines do not offer the same opportunity for support for women and children at more rural facilities or who cannot access a facility at all.

Officials from both the United Nations Population Fund (UNFPA) and UNICEF said that the country's experience with Zika had prompted the government to reflect and improve its treatment of people with



disabilities. One of the UNICEF officials we spoke with said, “Zika has represented an interesting opportunity for the country. It has shed light on important issues and on disabilities.” They added that today, “The Ministry of Health is cognizant that this is a serious issue and is confronting it from a surveillance and health care services perspective.” According to a UNFPA official, children born with Zika-related issues at San Salvadoran hospitals were being referred to a specialized health center. However, in terms of how to offer disability services more widely, the issue did not get past “discussions.” Unfortunately, for families living outside of San Salvador, which has the only specialized facility in the country, disability-related services for children were likely unavailable. Overall, people living outside the capital lack access to critical health services for Zika or otherwise and face deeper levels of poverty.

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

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.” 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.”

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

The Right to an Adequate Standard of Living

States are mandated to recognize the right to an adequate standard of living for everyone. This includes the right to adequate food, clothing, housing, and the continuous improvement of living conditions. 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. 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.”

The Right to Water and Sanitation

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



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Conclusion

According to several government and civil society interviewees, public attention related to the Zika virus dissipated after the peak of the outbreak in 2016. Nevertheless, the Ministry of Health maintained its commitment to tracking the mosquito that carries the virus and continued its vector control management strategy and virus surveillance methods through regular epidemiological reporting. The Ministry of Health also said that the clinical guidelines it issued with respect to microcephaly would help ensure that children impacted by the virus were connected to the services they needed to manage the related consequences for the rest of their lives. United Nations Children’s Fund and United Nations Population Fund (UNFPA) officials, however, remain concerned that people in El Salvador have let their guard down regarding Zika and are not making efforts to prevent further transmission. In fact, a representative from UNFPA said many people do not get treatment for arboviruses like Zika, meaning that the actual rate of transmission today may greatly surpass what has been officially reported.

While El Salvador has continued to track and monitor the virus as well as connect impacted families to care, there is still a great deal of progress that needs to be made, particularly in regard to the country’s record on human rights with respect to women’s reproductive health. Although some efforts have been made to increase the availability of contraception, access has not been implemented equitably across all regions and classes. Consequently, while the World Bank has reported that female adolescents are starting to receive contraception information, only 18% have reported using contraceptives.

Our research and visits to pharmacies and hospitals found that pharmacists and doctors continue to be gatekeepers in the provision of comprehensive sexual and reproductive health care. Unfortunately, we found that people in these positions often refuse to prescribe or sell contraception based on their own moral and religious objections. In cases of girls under the age of 18, parental consent may be required for medical procedures, which also proved to be a barrier for accessing contraception. In the context of Zika and other infectious diseases, the government must strongly consider the impact of these challenges, most notably on the rate of pregnancy among adolescent mothers at risk of Zika-related complications.

Given that legal abortion is still out of reach under the government’s total ban, those who wish to terminate a pregnancy due to Zika-related fears can expect nothing but criminal prosecution from their government. Indeed, nothing has changed since the women who comprise Las 17 were tragically imprisoned without fair trials after merely being suspected of having had abortions. While efforts are underway to end El Salvador’s total abortion ban, it remains to be seen if the country’s experience with Zika—and the ongoing risks faced by individuals who may become pregnant, especially given limited access to contraception—will influence the debate.

Recommendations



Government Recommendations

- Ensure that public education campaigns provide accurate, complete, and easily comprehensible information about the transmission of the Zika virus, including sexual transmission and its consequences. This should also include information about an individual's fundamental rights and policies related to protecting themselves against Zika and its side effects, including the right to free contraceptive methods and various social assistance programs.
- Provide access to free or affordable insect repellent to women of reproductive age, particularly during peak mosquito seasons and in areas with a high risk of contracting Zika and other arboviruses.
- Repeal restrictive anti-abortion legislation and permit exceptions for pregnancies resulting from sexual violence, rape, or incest, when there is a threat to the mother's life or health, or when the fetus is unviable.
- Amend El Salvador's legislation to remove the obligation that health care professionals and public officials report women suspected of having an abortion.
- Formulate and actively implement policies to provide the widespread dissemination of contraceptives (particularly emergency contraception) and accurate family planning information to allow women (particularly adolescents in rural areas) to exercise their reproductive rights.
- Liberate women who have been criminally punished following reported abortion-related offenses.
- Guarantee families and children affected by Congenital Zika Syndrome (CZS), particularly low-income families, access to social assistance programs necessary for their child's development and families' livelihood.
- Intensify efforts to eliminate mosquito-breeding sites and ensure long-lasting control of *Aedes aegypti* by investing in water and sanitation infrastructure for communities most susceptible to the spread of Zika and other arboviruses.
- Reduce disparities in available health care services in areas that have been particularly affected by violence and work within those communities to ensure all women can safely access those services.
- Ratify the Optional Protocol to the U.N. Convention on the Elimination of all Forms of Discrimination Against Women.



Health Care System Recommendations

- Increase the capacity of health care professionals to detect and diagnose Zika and provide consistent demographic data, including race/ethnicity, for reported cases to better document the social inequities of the epidemic.
- Ensure that surveillance systems to monitor Zika in rural and peri-urban areas as well as in areas affected by violence both inside and outside urban zones, are on par with systems in secure urban areas.
- Guarantee that all individuals, particularly adolescent and young women, have access to accurate information about the prevention of pregnancy and sexually transmitted infections, including the sexual transmission of Zika.
- Ensure that all pregnant women are able to access prenatal care early in their pregnancies and receive timely screening and treatment for Zika and other congenital infections, counseling on the prevention of Zika, including via sexual transmission, and sufficient supplies of condoms and insect repellent for them and their partners.
- Guarantee the provision of a second ultrasound to all pregnant women living in areas affected by Zika in order to facilitate early diagnosis of microcephaly.
- Provide access to psychosocial care for all pregnant women living in areas affected by Zika, particularly those who have been diagnosed with an infection during their pregnancy.
- Train health care professionals to properly diagnose and provide or refer care for infants with CZS.
- Conduct medical re-evaluations of all reported cases of CZS that were discarded for microcephaly during the early months of the epidemic to identify cases that may now fit the broader criteria.
- Train health care professionals on the importance of confidentiality and avoiding assumptions based on a patient's socioeconomic status, ethnicity, gender, or other factors.
- Ensure that women who wish to terminate a pregnancy receive accurate information about their legal options, including harm reduction where the procedure is not legally available.



Private Sector Recommendations

- Partner with the government to reduce the price and extend the distribution of quality diagnostic tests, safe insect repellent, necessary medications, and medical devices for the treatment of CZS.



Civil Society Recommendations

- Support ongoing social and digital media communication campaigns about Zika with an emphasis on community mobilization and educating individuals about their health-related rights and social assistance programs available to them.
- Monitor the implementation of long-term policies and programs related to sexual and reproductive health and social assistance for families and caregivers of children with disabilities.
- Foster greater collaboration between civil society actors working with various rights-based spheres and marginalized communities to not just promote, but use an intersectional human rights-based approach to tackle the Zika epidemic.
- Build strategic alliances with the international community, government officials, legislators, and influencers to continue exposing the harmful consequences of the absolute criminalization of abortion in El Salvador.

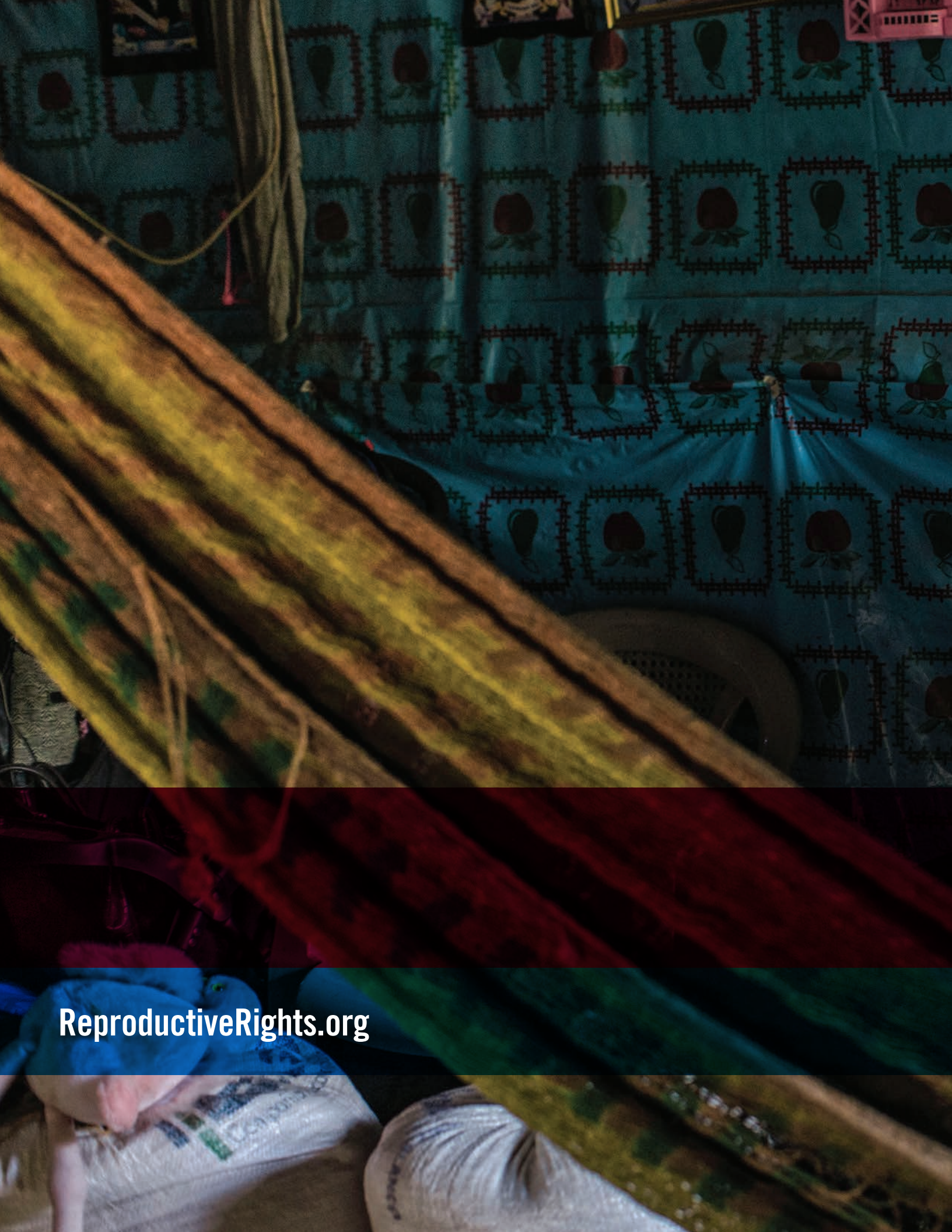
Endnotes

- ¹ These included formal interviews with five experts as well as informal discussions with three additional experts for the purpose of background information and snowball sampling. Interviewees included experts currently or formerly with the WHO, UNDP, OHCHR, and IACHR. Additionally, in completing the analysis herein, transcripts were reviewed from interviews with experts working for U.N. agencies and entities in the countries studied for this report, including UNFPA and UNICEF in Brazil, UNFPA and UNDP in Colombia, and UNFPA and UNICEF in Brazil.
- ² PAHO/WHO, *Zika Cases and Congenital Syndrome Associated with Zika Virus Reported by Countries and Territories in the Americas, 2015–2017: Cumulative Cases*, November 20, 2017. See also El Salvador Ministry of Health, Epidemiological Bulletins, EW 6 of 2017 and EW 52 2016 as cited in PAHO, Zika Epidemiological Report: El Salvador (Mar. 2, 2017) at 1. Figure 2 in the PAHO Epidemiological Report indicates that 33 cases per 100,000 people were reported in Chalatenango, 251 cases per 100,000 in Cabañas, and 249 cases per 100,000 in Cuscatlán.
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- ⁷ “WHO Director-General Summarizes the Outcome of the Emergency Committee Regarding Clusters of Microcephaly and Guillain-Barre syndrome,” WHO Media Centre, Feb. 1, 2016; Donald G. Neil Jr., “How the Response to Zika Failed Millions,” *New York Times*, Jan. 16, 2017; interview by authors with Joana (Mar. 2017).
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- ¹¹ Stephanie Nebehay and Julie Steenhuisen, “WHO Declares End of Zika Emergency But Says Virus Remains a Threat,” *Reuters*, Nov. 18, 2016; Donald G. McNeil Jr., “Zika Is No Longer a Global Emergency, W.H.O. Says,” *New York Times*, Nov. 18, 2016.
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- ¹³ UNFPA, UNFPA El Salvador, 2016.
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- ¹⁵ CDC, Zika: Symptoms, Testing, & Treatment, available at <https://www.cdc.gov/zika/symptoms/index.html>.
- ¹⁶ CDC, Zika: Symptoms, Testing, & Treatment, available at <https://www.cdc.gov/zika/symptoms/index.html>.
- ¹⁷ Pam Belluck and Tania Franco, “For Brazil’s Zika Families, a Life of Struggle and Scares,” *New York Times*, Mar. 11, 2017; see also CDC, Birth Defects: Facts About Microcephaly, Dec. 2016.
- ¹⁸ CDC, Birth Defects: Facts About Microcephaly, Dec. 2016.
- ¹⁹ CDC, Birth Defects: Facts About Microcephaly, Dec. 2016.
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- ²⁴ The original wording of Article 167 of the Salvadoran Penal Code is as follows: “el que promovere o facilitare la cirrupción de una persona menor de dieciocho años de edad o de un deficient mental, mediante actos sexuales diversos del acceso carnal, aunque la víctima consintiere participar en ellos, será sancionada con prisión de seis a doce años. (19) Cualquier persona familiar o particular que favorezca lo descrito en el inciso anterior será sancionada con la pena máxima aumentada en una tercera parte. (19)” (as was cited in International Planned Parenthood Federation and Coram Children’s Legal Centre, *Over-Protected and Under-Served: A Multi-Country Study on Legal Barriers to Young People’s Access to Sexual and Reproductive Health Services: El Salvador Case Study* (Mar. 2014) at 7.
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- ²⁷ 1998 Criminal Code, Article 312.
- ²⁸ Center for Reproductive Rights, *Marginalized, Persecuted, and Imprisoned – The Effects of El Salvador’s Total Criminalisation of Abortion*, 2014, p. 14 (hereinafter “CRR, Marginalized, Persecuted, and Imprisoned”).
- ²⁹ Center for Reproductive Rights, *Persecuted – Political Process and Abortion Legislation in El Salvador: A Human Rights Analysis*, 2001, p. 40 (hereinafter ‘Center for Reproductive Rights, Persecuted – Political Process and Abortion Legislation’).
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- ³² 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).
- ³³ WHO, *One Year into the Zika Outbreak: How An Obscure Disease Became a Global Health Emergency* (accessed June 30, 2017).
- ³⁴ See 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.
- ³⁵ See Convention on the Rights of Persons with Disabilities, adopted Dec. 13, 2006, art. 1, G.A. Res. A/RES/61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/61/611 (1980) (entered into force May 3, 2008). See also Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, adopted Jun 7, 1999, art. II, G.A. 29th Sess.
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