NEGLECTED AND UNPROTECTED
The Impact of the Zika Outbreak on Women and Girls in Northeastern Brazil
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Summary

On a Friday afternoon in October 2015, Luciana Caroline Albuquerque Bezerra, the executive secretary of health surveillance for the state of Pernambuco, Brazil, received a call from her boss, the secretary of health for the state. Two pediatric neurologists serving at separate hospitals had come to report a strange phenomenon: they each had seen an increase in the number of infants born with microcephaly—significantly smaller than average head circumference associated with incomplete brain development. By the following Monday, it was clear something was seriously wrong. The state health secretariat instituted a compulsory notification to the surveillance system of any new cases of babies born with microcephaly. Albuquerque was stunned as institutions around the state reported 600 new cases before the end of November, when in a typical year they might see only a dozen. She realized they were on the precipice of a new epidemic—but they had yet to discover its origin.

A few hundred kilometers away in the state of Paraíba, Adriana Melo, a physician specializing in high-risk pregnancies, was following the news from Pernambuco. She had seen two pregnant women in a short period of time whose sonograms showed unusual fetal brain development—microcephaly and other complications. She collected samples of amniotic fluid from both patients and sent them to Fundação Oswaldo Cruz (Fiocruz), a scientific institution in Rio de Janeiro, for analysis. Both samples tested positive for the Zika virus, establishing the first concrete link between microcephaly and the mosquito-borne illness.

No one is sure exactly when or how the Zika virus was introduced into northeastern Brazil, but the conditions for its rapid spread are ideal. Zika is transmitted predominantly through the bite of an infected *Aedes aegypti* mosquito, which has bred rampantly in the warm, humid climate of the states in the northeast. Research suggests that the 2015 El Niño climate phenomenon, occurring against the backdrop of climate change and steadily rising temperatures, was conducive for the transmission of Zika. The poorest region in the country, decades of underinvestment in public water and wastewater services exacerbated the proliferation of this mosquito, which can also carry other serious viruses, including dengue, chikungunya, and yellow fever. The outbreak hit as the country faced its worst
economic recession in decades, forcing authorities to make difficult decisions about allocating resources in response.

Dengue has been present in Brazil for decades, so when hundreds of thousands of people with cases of what was thought to be a milder case of dengue began arriving in health clinics in late 2014, it was worrying but not a surprise—until the wave of children born with microcephaly. State governments in the region tried to respond quickly, and in November 2015, the Brazilian government declared a national health emergency as cases of microcephaly increased. By February 2016, the World Health Organization had declared a global public health emergency in response to the spread of Zika. As of May 2017, the virus had been detected in 85 countries and territories around the world.

Nearly a year after the physicians first raised the alarm, Human Rights Watch began research in Pernambuco and Paraíba, two of the states hardest hit by the virus, to understand the human rights impacts of the Zika outbreak on women and girls, and on children with Zika syndrome. We spoke with more than 180 people, including more than two dozen mothers raising children with Zika syndrome and 44 women and girls who were pregnant or had given birth during the epidemic.

We found that the Zika virus outbreak in Brazil disproportionately impacted women and girls and aggravated longstanding human rights problems, including inadequate access to water and sanitation, racial and socioeconomic health disparities, and restrictions on sexual and reproductive rights. These problems existed long before the government confirmed local transmission of the Zika virus. However, the outbreak, and the national and international response to it, brought renewed attention to ongoing, unaddressed challenges to public health and human rights in Brazil. Human Rights Watch analyzed these human rights problems through the lens of the Zika outbreak. Our research found gaps in the Brazilian authorities’ response that have particularly harmful impacts on women and girls, and leave the general population vulnerable to continued outbreaks of serious mosquito-borne illnesses in the future.

The Brazilian authorities’ response to the Zika epidemic has centered on the fight against the mosquito, or vector control; access to services for affected populations; and technological development, education, and research. However, Brazilian authorities at all levels have not addressed systemic problems with public water and sanitation systems
that exacerbated the Zika crisis by contributing to ideal conditions for mosquito breeding. Years of dengue outbreaks should have made it abundantly clear that water and sanitation conditions are dangerous and require attention and investment, even among competing priorities. More than one-third of Brazil’s population lacks access to a continuous water supply. This intermittent access to water leaves people with no choice but to fill tanks and other containers with water for household use, which can unintentionally become potential mosquito breeding grounds if left uncovered and untreated. Poor wastewater infrastructure creates standing water in communities. On site visits in Pernambuco and Paraíba states, Human Rights Watch saw untreated sewage flowing into open, uncovered channels, storm drains, roads, or waterways near communities that are often obstructed with debris, creating dirty, standing water—ideal conditions for mosquito breeding, contrary to a false but popular belief that mosquitos only breed in clean water.

Since 2015, Brazil’s economy has suffered a deep recession, with high rates of unemployment and inflation. But long before the recent economic crisis, including in times of economic growth, government investments in water and sanitation infrastructure were inadequate. Years of neglect contributed to the water and wastewater conditions that allowed the proliferation of the *Aedes* mosquito and the rapid spread of the virus.

In 2007, after more than two decades of limited investments in sanitation, the National Congress enacted a new public law addressing sanitation, with implementing regulations adopted in 2010, boosting investments in the sector. Total investments grew from R$4,238 million in 2007 to R$12,175 million in 2015. Still, the expansion in the provision of sanitation services has been painfully slow. Management and institutional problems—including a simple lack of qualified projects—created bottlenecks in pushing funding out, a foreseeable risk after decades of underinvestment. In the context of the current economic recession, it will be difficult for Brazilian authorities to overcome the deficit in water and wastewater investments and to allocate the resources necessary to sustainably address failing systems.

Rather than planning additional investments in water and sanitation infrastructure to control mosquito breeding, the government’s national and state response to the Zika outbreak has focused quite narrowly on encouraging household-level efforts—namely cleaning water storage containers and eliminating standing water in homes—and spraying for mosquito eradication. Women and girls are often the ones responsible for these types
Raquel bathes her daughter Heloisa, a girl with Zika syndrome born in April 2016. Raquel says she cannot afford the medicines her twin daughters need for convulsions. © 2017 Ueslei Marcelino/Reuters

of vector-control tasks in the home. In an emergency phase, vector control focused on the household is key, but it is unsustainable in the long-term. Women’s and girls’ household efforts to control mosquito breeding are burdensome and often futile without state attention to structural water and sanitation failures.

In March 2016, the United Nations special rapporteur on the human rights to safe drinking water and sanitation stated, “There is a strong link between weak sanitation systems and the current outbreak of the mosquito-borne Zika virus, as well as dengue, yellow fever and chikungunya,” and added further that, “the most effective way to tackle this problem is to improve the failing services.”

Our research also looked into the nexus between the Zika outbreak and reproductive health. Many women and girls, frightened by the news of the epidemic, sought to avoid or delay pregnancy. However, many of those we spoke to said they found it difficult to avoid unplanned pregnancy—either because they lacked clear and accessible basic information
about reproductive health, or because they encountered barriers in accessing contraceptive methods, especially long-term ones. Our findings indicate that the Brazilian public health system may not be consistently providing comprehensive reproductive health information and services to some women and girls. In addition, the criminalization of abortion in Brazil forces many women to turn to clandestine, and often unsafe, procedures to terminate unwanted pregnancies—endangering their health and even their lives. In 2015, an estimated half a million women in Brazil had abortions, the vast majority performed clandestinely. Some doctors we interviewed had treated women and girls in the last year who had turned to caustic acid or other unsafe methods to try to induce abortion. A few women interviewed by Human Rights Watch had experienced or witnessed complications from unsafe abortion. Unsafe abortion remains the fourth-leading cause of maternal mortality in Brazil. Since 2005, at least 911 women have died from unsafe abortion in Brazil—largely preventable maternal deaths. Approximately 17 percent of the abortion-related deaths between 2011 and 2015 were adolescent girls and young women 10 to 19 years old.

The risk of Zika infection during pregnancy and the resulting consequences will likely lead even more women to seek unsafe and clandestine abortions. A July 2016 study published in *The New England Journal of Medicine* found a 108 percent increase in abortion requests from Brazil received by Women on Web—a nonprofit organization providing abortion medication in countries where safe abortion services are highly restricted—following a November 2015 Pan American Health Organization (PAHO) announcement related to Zika virus risks. The study concluded, “Ensuring reproductive autonomy through access to a full range of reproductive choices is currently a missing piece of the public health response to Zika.”

Pregnant women and girls interviewed for this report said that they often suffered anxiety and uncertainty related to the possibility of getting Zika during their pregnancies, and said that in their experience, the Brazilian public health system did not provide the information and support they needed to protect themselves from the virus. Many women and girls said that at their prenatal appointments they did not receive comprehensive information about how to prevent Zika transmission during pregnancy. Many interviewees did not know that Zika could be transmitted sexually, and therefore few of the pregnant women we spoke with were consistently using condoms to protect themselves and their fetus from Zika transmission during pregnancy.
In addition, some pregnant women and girls who believed, or feared, they had been exposed to Zika told Human Rights Watch they had difficulty accessing diagnostic tests or sonograms they needed to find out if they indeed had Zika or if their pregnancies could be impacted by the virus. Pregnant women from low-income households said they did not have the means to purchase mosquito repellent for everyday use.

Even as their stories fade from the headlines, the more than 2,600 children in Brazil born with microcephaly and other complications from the Zika virus—together now known as Zika syndrome—will need long-term support and care. Their primary caregivers are very often women whose lives are profoundly changed by having children with disabilities without receiving the full support they need from the government and society. Mothers raising children with Zika syndrome told Human Rights Watch they faced obstacles in accessing adequate information and support both at the time of delivery, and as their children grew and developed. They face difficulties buying expensive medicine, traveling to urban centers for appointments, and continuing paid work. Many mothers we interviewed expressed fears and doubts about what the future would hold for their children with Zika syndrome, particularly around access to state-supported services. Their fears and concerns are particularly relevant as Brazilian authorities enact fiscal austerity measures that may decrease funding for public health, education, and other services that could help children with Zika syndrome, and their caregivers, have the best possible quality of life in the long-term.

In December 2016, the National Congress approved a constitutional amendment freezing public spending for a period of 20 years, adjusting only for inflation. Before the amendment was passed by Congress, the Oswaldo Cruz Foundation (Fiocruz), a public research and health technology institution, published a letter to the federal government and National Congress warning that the proposed amendment, if approved, “would result in significant harm to people’s health and life.” Fiocruz raised particular concerns regarding how the amendment could affect Brazil’s capacity to respond to Zika and other epidemics: “The question is: how to ensure control of epidemics such as Zika, dengue and chikungunya, including research, assistance, vector control, medicines, and necessary vaccines, with a freeze on resources? In particular, the impact on research, fundamental to new products and new solutions that are already underfunded in our country, will be incalculable, compromising in the long term the capacity for response and national autonomy.”
The United Nations special rapporteur on extreme poverty and human rights, Philip Alston, called the bill “a radical measure, lacking in all nuance and compassion.” He added, “It will hit the poorest and most vulnerable Brazilians the hardest, will increase inequality levels in an already unequal society, and definitively signals that social rights are a very low priority for Brazil for the next 20 years.” The constitutional amendment took effect in early 2017, and further austerity measure remain under discussion by the government and National Congress.

The national, state, and local response to the Zika outbreak should not overlook men and boys or reinforce gender stereotypes about health and caregiving. When health authorities fail to communicate clear information about the sexual transmission of the virus, many people perceive the prevention of Zika transmission during pregnancy as the sole responsibility of pregnant women.

Women interviewed for this report and some of their male partners spoke of the need for the authorities to support fathers as well as mothers in their efforts to prevent Zika transmission and to address the economic and psychosocial burdens of rearing children affected by the Zika virus. Providers told Human Rights Watch that fathers needed additional support to actively participate in caregiving. One father of a child with Zika syndrome in Pernambuco state described the need for more outreach by service providers and support organizations to fathers raising children impacted by the virus, to facilitate their role in supporting their partners and addressing their children’s needs. “The mothers are warriors,” he said, using the Portuguese word “guerreiras.” “I think the fathers sometimes are absent, but the mothers are always here.” But, he said that he does not believe it has to—or should—be this way. Authorities should avoid reinforcing negative gender stereotypes in policies or messaging around the prevention of Zika and in the provision of services to families affected by it.

In February 2017, the director-general of the World Health Organization declared the Zika epidemic was no longer a public health emergency of international concern, and stated, “WHO and affected countries need to manage Zika not on an emergency footing, but in the same sustained way we respond to other established epidemic-prone pathogens, like dengue and chikungunya, that ebb and flow in recurring waves of infection.” She added, “Zika revealed fault lines in the world’s collective preparedness. Poor access to family
planning services was one. The dismantling of national programmes for mosquito control was another.” The juxtaposition of these statements is not an accident.

In May 2017, the Brazilian government declared that the national public health emergency related to the Zika virus had ended, 18 months after physicians in the northeast first identified a link between Zika and microcephaly. The number of Zika virus cases, and the number of infants born with disabilities linked to the virus, were dramatically lower during the first few months of 2017, as compared to same period in 2016. Still, the underlying conditions that allowed the outbreak to escalate in Brazil remain largely unaddressed, leaving the population vulnerable to future outbreaks.

As Brazil moves to confront the long-term implications of the Zika outbreak, authorities should take additional steps to address the underlying contexts that made its initial impacts so severe. Without government investments in water and sanitation infrastructure, outbreaks of serious, and potentially fatal, mosquito-borne viruses could continue to threaten public health in Brazil. In order to ensure the fundamental human rights of women and girls, the government should guarantee they have access to comprehensive reproductive health information and services, including full autonomy to voluntarily terminate pregnancies. The government should also ensure that children with Zika syndrome, and their caregivers, have long-term access to a range of services to have the best possible quality of life. Mothers and providers interviewed for this report feared that the state would forget children affected by the virus as the rate of new cases decreased, and media and public attention to the outbreak dwindled.

Under international human rights law, Brazil's population has the right to sufficient, safe, and affordable water and sanitation. Persons with disabilities and their families have the right to an adequate standard of living. The government has an obligation to ensure access to reproductive health information and services. It is also obligated to eliminate excessive restrictions on access to safe and legal abortion. This report examines the Brazilian government’s human rights obligations as they relate to its response to the Zika epidemic, including its failure to meet its obligations related to women’s reproductive rights.

These human rights guarantees should guide Brazil's efforts moving forward. A human rights-based approach to the Zika outbreak should address, in particular, gaps in fulfilling the rights to water and sanitation, women’s and girls’ reproductive rights, and the rights of
persons with disabilities and their caregivers. To better respect and protect human rights, national, state, and local authorities should work collaboratively to:

- Address pervasive problems affecting the rights to water and sanitation to stem the spread of mosquito-borne illnesses. A household approach to vector control will fail in the long-term if systemic problems are not also addressed.
- Take concerted action to reduce unplanned pregnancies by providing women and girls with comprehensive reproductive health information and services, including long-term contraceptive options, and identify and resolve any gaps in distribution or challenges in access.
- Provide pregnant women and their partners full and accurate information and services to prevent Zika virus transmission during pregnancy, including related to the sexual transmission of Zika.
- Provide sustained support for the short and long-term services to families raising children with Zika syndrome that will allow children affected by the virus, and their family members, to live with dignity.
- Engage men and boys in preventing unplanned pregnancy, combatting the spread of Zika virus, and ensuring that children with Zika syndrome have support.

As a matter of urgency, the National Congress should enact legislation to decriminalize abortion to ensure that women and girls do not have to resort to life-threatening clandestine procedures to terminate pregnancies they do not want to continue.

As one woman whose child has Zika syndrome told Human Rights Watch, “there's a big opportunity to pay attention and prevent other cases in the future.” If the Brazilian authorities at federal, state, and local levels do not act, the risk that women and girls will continue to be impacted by the Zika outbreak, or future epidemics, will remain.
Recommendations

To National, State, and Municipal Health Authorities

*Improve Zika Virus Prevention, Detection, and Response*

- Ensure integrated efforts across all levels of government to combat *Aedes* mosquitoes and prevent transmission of Zika and other mosquito-borne viruses.
- Establish inter-ministerial or inter-agency working groups at the national, state, and municipal levels to ensure close collaboration among water, sanitation, and environmental authorities in addressing vector control in the short, medium, and long-term.
- Strengthen epidemiological surveillance systems to identify all cases of Zika virus and congenital Zika syndrome, including monitoring past early infancy.
- As part of a comprehensive response to combat the transmission of the Zika virus, ensure that national, state, and municipal prenatal care protocols include the following:
  - Comprehensive counseling on Zika virus prevention as a mandatory component of all initial prenatal clinical visits. Ensure counseling includes evidence-based information on the sexual transmission of Zika, and the importance of condom use during pregnancy;
  - Full access to Zika diagnostic testing and sonograms, including voluntary fetal anomaly scans, for pregnant women and girls who believe they have been exposed to the Zika virus and wish to perform the scan. Ensure results of tests are explained fully and shared in a timely fashion; and
  - Access to high-quality and regular psychological support services for women and girls whose pregnancies are impacted by the Zika virus, and for their partners. Offer psychological support at the first indication of an anomaly in the pregnancy, and continue throughout the pregnancy, and during and after delivery.
- Make insect repellent accessible to all pregnant women free of charge in the public health care system.
- Revise national, state, and local public education and awareness-raising campaigns and communications related to the Zika virus to ensure that they
include the best scientific evidence on Zika prevention, including sexual transmission, and the consequences of the virus, particularly when pregnant women are exposed. Review materials to ensure they do not disproportionately, or unfairly, suggest that women and girls should bear the burdens of Zika prevention. Include the roles of responsibilities of men and boys in Zika virus prevention.

- Ensure national, state, and, local health protocols are regularly reviewed and updated to reflect new developments in the scientific literature related to the Zika virus and the evolving needs of children born with Zika syndrome.
- Ensure that national, state, and local public education efforts and individual counseling engage couples and men, and do not single out pregnant women alone to bear the burden of preventing Zika transmission during pregnancy. Efforts should ensure men understand their risk of transmitting Zika to their partners and are encouraged to get tested before trying to conceive. If a woman is already pregnant, her partner should receive counseling on the benefits of condom use during the pregnancy to prevent Zika and other sexually transmitted infections.

Provide Comprehensive Sexual and Reproductive Health Care

- Expand access to long-acting reversible contraceptives and voluntary sterilization through the public health system to reduce unplanned pregnancies.
- Update relevant national, state, and local health protocols to ensure men and boys receive counseling and information about contraceptive and family planning methods, and access to condoms and voluntary sterilization.
- Ensure that all relevant national, state, and local reproductive healthcare protocols include the following:
  - A screening process to determine whether pregnant women and girls planned and wanted their pregnancies, and what options may be available to those with unplanned pregnancies, including legal abortion;
  - Harm reduction counseling and information on post-abortion care for women and girls who indicate that they may terminate pregnancies clandestinely; and
  - Routine post-delivery contraceptive counseling to ensure all women and girls who give birth have comprehensive and accurate information about how to prevent pregnancy.
• Develop and implement an extensive training program to ensure all health care providers can competently and consistently implement sexual and reproductive health protocols, including the provisions listed above.

To the Ministry of Health

• Establish a task force to address gaps in Brazil’s reproductive health services and to identify barriers in accessing family planning information and services, particularly for traditionally underserved or vulnerable populations, including adolescent girls, older women, people of color, and those from low-income communities.
• Conduct a national study leading to the adoption of measures to ensure that women and girls can access legal abortion services as provided under the law and the 2011 technical norm, without geographic or institutional obstacles. Based on the outcome, update the technical norm to address any undue obstacles identified.
• Ensure universal access to abortion services, when legal, within the national health system and in all Brazilian states.
• Develop an extensive training program to ensure all providers can competently and consistently implement all Zika-related and sexual and reproductive health protocols, including the provisions listed above. Work with state and local health authorities to implement the training.

To National, State, and Municipal Authorities Across Sectors

Support Families Raising Children with Zika Syndrome

• Compile data on confirmed cases of children with Zika syndrome and availability of service providers with the training and capacity to treat them. Map out areas where additional services are needed consistent with the evolving needs of children born with Zika syndrome. To the extent possible, channel resources to areas where additional coverage is needed.
• Ensure both male and female caregivers, and family members of children with Zika syndrome, have full access to ongoing psychological support as needed.
• Examine bureaucratic processes required for families with Zika syndrome to access specialized services in facilities outside of the municipalities where they live.
Streamline and simplify these processes to ensure families raising children with Zika syndrome are not forced to delay treatment due to procedural hurdles.

- Expand access to safe, reliable, state-funded transportation services for families to bring their children with Zika syndrome to appointments and consultations as well as to other fundamental services as appropriate, like education, health, and rehabilitation.
- Elicit feedback from families raising children with Zika syndrome about their long-term needs.

**Support Children with Zika Syndrome**

- Develop and carry out an educational policy to include children with Zika syndrome in the educational system. Develop and conduct an extensive training program to ensure all early childhood caregivers and educators can serve the children and address their needs competently and consistently.
- Develop initiatives to include children with Zika syndrome in alternative care programs, such as foster families or extended families, in case their own families are temporarily unable to provide adequate support.
- Develop specific programs to ensure children with Zika syndrome and other disabilities are not placed in residential institutions, and have appropriate long-term alternative care.
- Develop early intervention programs, beginning at the earliest possible stage, to adequately stimulate and habilitate children with Zika syndrome, based on multidisciplinary assessments, particularly in the areas of health, education, and social services. Establish and maintain services for children with Zika syndrome as close as possible to their own communities, in both urban and rural areas.

**To National, State, and Municipal Authorities engaged on Environmental, Water, and Wastewater Infrastructure and Investments**

- Establish inter-ministerial or inter-agency working groups at the national, state, and municipal levels to ensure close collaboration with health, water and sanitation, and environmental authorities engaged in short-term vector control to
ensure that medium and long-term efforts are adopted and implemented by non-
health agencies or authorities.

- Audit water, sanitation, and wastewater assets to determine whether they are
  contributing to mosquito breeding and implement a plan to address vector control
  at the site of assets.

- Adjust capital investments and planning in water, sanitation, and wastewater
  services to be targeted to communities most affected by mosquito-borne outbreaks.

- Ensure capital investments and planning in water, sanitation, and wastewater
  services reflect a whole of government approach to mosquito eradication and
  vector control.

- Revise climate change policies to include strategies to address increased risks of
  vector-borne diseases like Zika and their impact on women’s human rights.
  Ensure that the National Adaptation Plan and other climate change adaptation
  policies include strategies to address the increased risks women face from
  vector-borne illnesses.

To the National Congress

- Amend Law No. 13,301 of 2016 to ensure all families raising children with Zika
  syndrome have access to the financial benefit (Benefício de Prestação Continuada)
  provided to individuals with disabilities in Brazil. Ensure that all children with long-
  term health complications related to Zika transmission, not just those with
  microcephaly, are eligible for consideration.

- Repeal criminal code provisions that criminalize abortion, especially those that
  punish women for inducing abortion or doctors for providing safe abortion services.

- Enact laws to provide women and girls with access to voluntary and safe
  abortion services.

- Amend the Family Planning Law No. 9,263 of 1996 to ensure access to family
  planning services and respect women’s reproductive autonomy. Exclude
  requirements of age and number of children to access permanent contraceptive
  options.
To the Supreme Court of Brazil

- To the extent permitted under domestic law, consider the relevance and applicability of Brazil’s international human rights obligations in relation to constitutional petitions related to women’s reproductive rights, as detailed in the amici curiae submitted to the court by Human Rights Watch in April 2017.

UNFPA, UNICEF, WHO, Other UN Agencies and Donors

- Provide support for ongoing monitoring and surveillance of Zika and other mosquito-borne viruses, including across geographic borders.
- Provide guidance as well as technical and other support to Zika-affected countries for eradication efforts, reproductive health services, and research.
- Support and help implement long-term programs to support children with Zika syndrome and help their families achieve the best possible quality of life.
- Support continued research on the long-term impacts of Zika and ensure knowledge sharing.
- Facilitate development and sharing of best practices for Zika testing, diagnosis, and eradication efforts.
- Eliminate all restrictions to foreign assistance that limit the exercise of fundamental human rights, including sexual and reproductive rights.
Methodology

Human Rights Watch conducted research for this report in late 2016 and early 2017 in two states in the northeast region of Brazil, Pernambuco and Paraíba. Most interviews were carried out in two cities: Recife, in Pernambuco state, and Campina Grande, in Paraíba state. Many interviewees resided in other parts of the two states but regularly traveled to one of these two cities to access health services or services for children with Zika syndrome.

We interviewed 98 women and girls ages 15 to 63, including 44 who were pregnant or had recently given birth, and 30 who were raising children with Zika syndrome; nine men, ages 19 to 62, who lived in communities affected by the Zika outbreak, four of whom were the partners of women and girls interviewed for the report; 25 service providers; and 27 other experts, such as prosecutors, public defenders, academic researchers, and representatives of nongovernmental organizations (NGOs). Human Rights Watch also interviewed health and sanitation authorities from national, state, and local government entities, including the Ministry of Health, Ministry of Cities, the Pernambuco and Paraíba Secretariats of Health, the Recife Secretariats of Health and Sanitation, and others. In total, Human Rights Watch interviewed 183 people for this report.

Human Rights Watch identified interviewees through outreach at medical facilities and in communities affected by the Zika virus, with the assistance of advocates, researchers, service providers, and NGOs.

Most interviews were conducted in Portuguese, at times through interpreters. When possible, Human Rights Watch held interviews individually and in private, though in some cases, interviewees preferred to have another person present. Interviews were primarily held in homes, community spaces, and medical facilities.

Human Rights Watch informed all interviewees of the purpose of the interview, its voluntary nature, and the ways in which the information would be collected and used. Interviewers assured participants that they could end the interview at any time or decline to answer any questions, without any negative consequences. All interviewees provided verbal informed consent to participate.
Interviews were semi-structured and covered topics related to reproductive health, access to information and services, and environmental conditions in the context of the Zika virus epidemic. Most interviews lasted 30 to 60 minutes, and all interviews took place in person. Care was taken with victims of trauma to minimize the risk that recounting their experiences could further traumatize them. Where appropriate, Human Rights Watch provided contact information for organizations offering legal, counseling, health, or social services. Human Rights Watch did not provide anyone with compensation or other incentives for participating.

Human Rights Watch also analyzed relevant laws and policies and conducted a review of secondary sources, including epidemiological data, public health studies, reports from the World Health Organization and the Brazilian national, state, and local health entities, and other sources.

The names of women, girls, and men interviewed have been changed to protect their privacy and safety, unless they requested their real name be used. Names of service providers, officials, and experts have not been changed. A few requested anonymity, which is noted in the relevant footnotes.

In this report, the word “child” refers to anyone under the age of 18, with “girl” referring to a female child.

Human Rights Watch did not use a random sampling method to identify interviewees. The experiences of the individuals we interviewed may not be representative of the broader population of the northeast region, nor of the country as a whole. However, Human Rights Watch found patterns and similarities in the experiences of interviewees from a range of cities and towns across two states. Our research strongly suggests many other women and girls in Brazil face similar challenges related to their sexual and reproductive rights, and access to information and services in the context of the Zika outbreak.
I. Background

In 2015, the first confirmed cases of Zika virus infection in Brazil put the country at the epicenter of a new epidemic. The public health crisis that followed exacerbated the difficult living conditions of many marginalized communities, and at the same time, was itself exacerbated and amplified by inadequate access to water and sanitation, racial and socioeconomic health disparities, and restrictions on sexual and reproductive rights. Though these problems existed long before the government confirmed local transmission of the Zika virus, the outbreak, and the national and international response to it, brought renewed attention to longstanding challenges to public health and human rights in Brazil, including the rights to water and sanitation and sexual and reproductive rights.

The Zika Virus Outbreak in Brazil

Though scientists first identified the Zika virus in humans in Africa in 1952, the first large outbreak occurred decades later, in Micronesia in 2007. In 2013 and 2014, outbreaks occurred in four other groups of Pacific islands.¹

In late 2014, health officials in the northeast of Brazil began reporting cases of an illness characterized by skin rashes and fever. By May 2015, health authorities confirmed local transmission of the Zika virus in Brazil. At the time, complications related to pregnancy were unknown. In 2016, Brazil’s Ministry of Health reported 214,193 probable cases and 128,266 confirmed cases of Zika virus,² though many more cases were likely unreported. The government estimated there were somewhere between 500,000 and 1.5 million cases from 2015 through early 2016.³ Since the emergence of Zika in Brazil, the virus has spread

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to many countries. As of May 2017, 85 countries and territories have reported documented instances of Zika virus transmission.\(^4\)

The Zika virus is transmitted predominantly through the bite of an infected *Aedes aegypti* mosquito. The virus can also be transmitted during pregnancy from a woman to her fetus, and through unprotected sexual activity.\(^5\) Individuals infected with Zika virus are often asymptomatic, or present mild symptoms, such as fever, muscle and joint pain, conjunctivitis, and rash.\(^6\) Blood and urine tests can confirm Zika infection.\(^7\)

Zika is associated with serious neurological complications, particularly when a pregnant woman becomes infected and her fetus is exposed to the virus in utero. Confirmed infection in the first trimester poses the highest risk, with 15 percent of babies born with disabilities.\(^8\) The outbreak in Brazil has been linked to the birth of thousands of babies born with atypical brain development and other complications including seizures, problems with hearing and sight, musculoskeletal differences, and microcephaly, when the brain and head are underdeveloped. Together, the range of complications observed in infants that were exposed to Zika virus in utero are referred to as congenital Zika syndrome.\(^9\) Research

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suggests that infants who were exposed to Zika prenatally and born without microcephaly may develop microcephaly and other problems with brain development after birth.\textsuperscript{10}

The virus has also been identified as a trigger for Guillain-Barré syndrome, a rare neurological disorder that can lead to paralysis and death in severe cases, with most people recovering fully in the course of weeks or months.\textsuperscript{11} According to the World Health Organization, “There is scientific consensus that Zika virus is a cause of microcephaly and Guillain-Barré syndrome.”\textsuperscript{12}

Brazil accounts for the overwhelming majority of cases of congenital Zika syndrome worldwide.\textsuperscript{13} The Ministry of Health began tracking an unprecedented increase in cases of babies born with microcephaly in October 2015.\textsuperscript{14} Between 2015 and April 2017, there were 2,698 confirmed cases of Zika syndrome in infants in Brazil, and more than 3,000 remain under investigation.\textsuperscript{15} Media reports suggest that not all state and municipal health authorities are accurately notifying cases, so this may be an undercounting.\textsuperscript{16} In the state of Rio Grande do Norte, an audit carried out by the Ministry of Transparency reported cases


\textsuperscript{14} Heukelbach et al., “Zika Virus Outbreak in Brazil,” Journal of Infection in Developing Countries, pp. 116-120.


\textsuperscript{16} According to unpublished Ministry of Health data obtained through an information request by the Spanish newspaper El País, while the Ministry of Health’s bulletin registered 18 suspected cases until the second week of 2016, municipalities had notified 210 cases, and 159 births between November and December. São Paulo’s health authorities argued the discrepancy was that they reported microcephaly cases with evidence of Zika infection only. Talita Bedinelli, “São Paulo desrespeita regra federal e não reporta o nascimento de quase 200 bebês com microcefalia,” El País, January 26, 2016, http://brasil.elpais.com/brasil/2016/01/25/politica/1453755744_022637.html (accessed March 24, 2017). One month earlier, the Brazilian newspaper Estadão reported that 18 cases had not been included in the national bulletin. Fabiana Cambriocli, “Cidades paulistas apuram 18 casos de microcefalia,” Estadão, December 8, 2015, http://saude.estadao.com.br/noticias/geral,cidades-paulistas-apuram-18-casos-de-microcefalia,10000004157 (accessed March 24, 2017).
of mayors failing to report suspected cases of Zika syndrome so that they do not reflect badly on the municipality.\textsuperscript{17}

According to Ministry of Health data, the number of Zika virus cases, and the number of infants born with disabilities linked to the virus, were dramatically lower during the first few months of 2017, as compared to 2016.\textsuperscript{18}

Climatic, Water, and Wastewater Context

Brazil’s humid, tropical climate—particularly in the rainy season—have contributed to the proliferation of mosquitos and the rapid spread of Zika and other mosquito-borne diseases. The Zika epidemic in Brazil may have been fueled by unusual climatic conditions during the time of its outbreak. A recent study suggests that exceptionally high temperatures related to the 2015 El Niño climate phenomenon, occurring against the backdrop of steadily rising temperatures because of climate change, were conducive to the transmission of Zika in South America.\textsuperscript{19} With rising temperatures, the reproductive cycle of the mosquitos accelerates: the higher the air temperature, the faster the virus reproduces in the mosquito for transmission to another person. Higher temperatures can also cause the mosquitos to mature faster. Droughts, exacerbated by climate change, can also be a cause for disease spread if households store more water in containers that provide suitable mosquito breeding sites.\textsuperscript{20}

Over the coming decades, climate change is likely to increase the spread of mosquitos carrying vector-borne diseases.\textsuperscript{21} While the relationship between Zika and climate


\textsuperscript{21} Ibid.
change still needs further research, a recent study suggests that the potential worldwide habitat range for *Aedes* mosquitos carrying Zika and other diseases could increase by more than 10 percent by 2061-2080, as a result of high greenhouse gas emissions and population growth.22

The Brazilian national government has developed several policies to address the effects of climate change, including a National Plan on Climate Change (2008), a Sector Health Plan for Mitigation and Adapting to Climate Change (2013) and a National Adaptation Plan to Climate Change (2016). The National Adaptation Plan to Climate Change (NAP) recognizes that “issues of race and gender” are “contributing factors” to social vulnerability and that certain socioeconomic groups are disproportionately impacted by climate change.23 The NAP also acknowledges the importance of utilizing “gender-sensitive” criteria to develop adaptation measures.24

While cognizance of issues of race and gender in these policies is encouraging, the NAP does not include a gendered analysis in its Strategy for Vulnerable Populations. When discussing steps to mitigate the impacts of climate change, the NAP considered how several socioeconomic groups, including Indigenous peoples, family farmers, and fishermen, were particularly vulnerable to these impacts. The NAP, however, fails to consider how women were affected by climate change.

The NAP also acknowledged that climate pattern changes “impact the vectors of some diseases” and that effects of climate change, such as “change in rainfall patterns and increased frequency of extreme climate events, associated with factors such as poor sanitation” reduce the availability of drinking water, which, in turn, exposes populations to vector-borne diseases.25 The NAP fails to recognize that women face increased risks from vector-borne diseases, such as Zika.

Poor water and wastewater conditions also contribute to mosquito population growth. In a joint statement released in March 2016, several UN experts explained how poor access to public water and sanitation services contribute to the spread of Zika and other viruses. Leilani Farha, the UN special rapporteur on adequate housing, said, “When people have inadequate living and housing conditions, where they do not have access to safely managed water services, they tend to store water in unsafe ways that attract mosquitoes. In addition, poor sanitation systems where wastewater flows through open channels and is disposed of in unsafe pits leads to stagnant water and unfit housing—a perfect habitat for breeding mosquitoes.”

More than one-third of Brazil’s 208 million people do not have access to a continuous water supply, while 3.8 million lack any access to safe drinking water. Residents who lack continuous access to water must store water in tanks, buckets, and other containers. If left uncovered and untreated, stored water can be a breeding ground for mosquitoes. Aedes mosquitoes—which carry Zika as well as other serious mosquito-borne viruses, including dengue, chikungunya, and yellow fever—lay eggs in containers filled with standing water, including those used for domestic water storage. They also lay eggs in objects where water can collect like used tires and discarded food and beverage containers filled with rain.

Poor garbage collection services could also contribute to the proliferation of mosquitoes. In 2014, approximately 55.7 percent of the population had access to adequate garbage collection services, while 32.7 percent were covered by a precarious service and 11.6 percent did not have access to any kind of service.

More than 35 million people in Brazil lack adequate sanitation services—provision of facilities and services for the safe disposal of human urine and feces. Millions more do not have adequate wastewater or fecal sludge management for their homes or communities, as a result of which untreated sewage is dumped into storm canals and waterways, which along with other solid waste obstructs the flow of water and creates standing and stagnant water. Only an estimated 50 percent of the population was connected to a wastewater system in 2015, and less than 43 percent of the country’s total volume of wastewater was treated. In the northeast region of the country, the situation is even worse: in 2015 less than 25 percent of the population was connected to a wastewater system, and only 32 percent of wastewater was treated.

In Brazil, federal, state, and municipal governments share the responsibility for developing and implementing sanitation policies. The three have jurisdiction to regulate it under the guidelines set by the federal government which is also the main financier. While municipalities bear the original jurisdiction over the provision of water and sanitation services, states, through public companies, have often assumed the provision of these services, as in the cases of Pernambuco and Paraíba. Thus, a response to improving the conditions requires the cooperation of all levels of government.

Responding to climatic changes and the poor water and wastewater conditions will be key to the long-term reduction of Zika transmission, but is also urgent due to other serious, and potentially fatal, mosquito-borne viruses threatening public health in Brazil. The largest outbreak of dengue virus in recent history took place in 2013, but there were still more than 1.5 million cases of dengue, and more than 640 confirmed deaths, registered in

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Brazil last year. The incidence of chikungunya in Brazil has increased dramatically in recent years. From 2015 to 2016, the number of cases of chikungunya increased nearly sevenfold, from approximately 38,000 in 2015 to more than 265,000 in 2016, overwhelmingly in the northeast region of the country.

Since December 2016, Brazil has also had a surge in yellow fever, with hundreds of confirmed cases and at least 240 deaths. The yellow fever outbreak is the largest in Brazil since health officials began tracking the virus in 1980. As of May 31, 2017 health authorities had reported more than 3,200 suspected cases in 17 states, transmitted by *Haemagogus* and *Sabethes* mosquitos found in rural areas, and 792 confirmed cases in nine states (Minas Gerais, Espírito Santo, São Paulo, Rio de Janeiro, Pará, Tocantins, Mato Grosso, Goiás and Distrito Federal). Reports also suggest a high number of epizootic transmission in non-human primates. If the virus reaches urban areas, and *Aedes* mosquitos begin transmitting it, the number of cases could increase dramatically.

**Marginalized Populations Vulnerable to the Zika Outbreak**

The long-term impacts of the Zika outbreak have fallen disproportionately on young, single women and girls of color. The northeast region of Brazil, one of the poorest in the country,
accounts for more than three-quarters of the confirmed cases of babies born with Zika syndrome since the start of the epidemic.\textsuperscript{42}

Unpublished Ministry of Health data obtained through an information request by the Brazilian publication \textit{Estadão}, suggests that roughly one-quarter of the women and girls who gave birth to babies with microcephaly between November 2015 and September 2016 were under the age of 20 (by comparison only 18 percent of pregnancies occur among adolescents under 20).\textsuperscript{43} More than 760 adolescent girls and young women ages 10 to 19 gave birth to babies with microcephaly during that period,\textsuperscript{44} including 35 girls ages 10 to 14.\textsuperscript{45} It should be noted that girls under 14 in Brazil are considered below the age of the sexual consent, regardless of the age of their partners.\textsuperscript{46}

Nearly half—48 percent—of women and girls who gave birth to babies with microcephaly are single (as compared to 40 percent in the general population) and more than three-quarters identify as “black” (preta) or “brown” (parda) (as compared to 59 percent in the general population).\textsuperscript{47}

Sexual and Reproductive Health and Rights in Brazil

In January 2016, amid scientific uncertainty around the long-term impacts of Zika virus, authorities from several countries in Latin America recommended that women delay pregnancy.\textsuperscript{48} Their recommendations sparked new public discussions about access to


\textsuperscript{44} This includes microcephaly from all causes, not just Zika-related cases.


\textsuperscript{46} Human Rights Watch interview with Ana Carolina Thé, Analista Ministerial Medica, Promotoria de Saúde, and Westei Conde y Martin Junior, Promotor de Justica, Procuradoria Geral de Justica, Ministerio Publico, Recife, Pernambuco, Brazil, September 13, 2016.

\textsuperscript{47} Cambricoli, “1/4 das mães de bebês com microcefalia é adolescente,” \textit{Estadão}.

sexual and reproductive health information and services in countries affected by the epidemic. Brazil, as the epicenter of the epidemic, issued a protocol that highlighted women’s access to contraception as a key pillar of the response to the epidemic, but failed both to recognize the significant barriers women face to access contraception or what to do in case of contraceptive failure. Recently, the Ministry of Health developed a new integrated plan against the Zika epidemic, which included a focus on sexual and reproductive health, for municipalities in six states—Maranhão, Ceará, Rio Grande do Norte, Alagoas, Sergipe and Bahia. The most recent protocol on public health emergencies, released in December 2016, increased the list of actions related to sexual and reproductive health and rights, including a recommendation on the use of condoms during pregnancy.

Women and girls in Brazil have constitutional and statutory guaranteed rights to access contraception for free in many forms at local health centers run by the national health system (Sistema Único de Saúde, or SUS). Despite this, a national demographic and health study published in 2008 found that nearly half of pregnancies in Brazil are unplanned or unwanted, indicating unmet contraceptive need. Likewise, a more recent study published in 2016 involving nearly 24,000 Brazilian women who had recently given birth.

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51 Human Rights Watch interview with Thereza de Lamare, Ministry of Health official, Brasilia, April 19, 2017.
birth found that 55 percent reported that their most recent pregnancies were unintended.\textsuperscript{55} Younger, single, women and girls of color without paid employment and with fewer years of schooling were more likely to report their pregnancy was unintended.\textsuperscript{56} Consistent with these findings, the UN estimates more than 2.3 million Brazilian women and girls ages 15 to 49 who are married or in unions have an unmet need for family planning.\textsuperscript{57} These estimates reflect the need prior to the outbreak, and do not include women and girls who are not married or in unions.

Adolescents may have greater unmet need for contraception than other segments of the population. Nearly 20 percent of live births in Brazil are to adolescent women and girls ages 10 to 19, accounting for more than 560,000 births per year.\textsuperscript{58} A national survey involving nearly 1,000 sexually active young women and girls ages 15 to 19 in 2013 found that 21 percent were not using any method of contraception, and only 17 percent had visited a public health agent to discuss family planning in the 12 months prior to the survey.\textsuperscript{59}

Women and girls in Brazil who become pregnant and wish to terminate unplanned pregnancies have few legal options for accessing abortion. Abortion is legal in Brazil only in cases of rape, when necessary to save a woman’s life, or when the fetus suffers anencephaly, a fatal congenital brain disorder.\textsuperscript{60} According to the criminal code, women and girls who terminate pregnancies under any other circumstances are subject to criminal


\textsuperscript{56} Ibid.


\textsuperscript{60} Government of Brazil, Penal Code, Decree-Law Number 2.848, art. 128; Justice Marco Aurélio, “Arguição de Descumprimento de Preceito Fundamental 54 Distrito Federal,” 2012. Yet, women and girls in Brazil who have the right to terminate pregnancies legally face obstacles in accessing legal abortion services. A study published in 2016 found only 37 institutions in the country offered legal abortion, mostly concentrated in capitals and large cities. Legal abortion services were not available at all in seven states. Alberto Pereira Madeiro and Debora Diniz, “Legal Abortion Services in Brazil – A National Study,” Ciência & Saúde Coletiva, vol. 21, no. 2 (2016), pp. 563-572.
punishment of up to three years in prison, while people who perform abortions face up to four years, if convicted.61 According to some media reports, in 2014 alone at least 33 women were arrested for abortion, and seven of them were denounced by doctors after having come to hospitals in need of post-abortion care. One of them spent three days handcuffed to a bed.62

National and International Response to the Epidemic

In November 2015, as cases of microcephaly increased, the Brazilian government declared a public health emergency of national concern and created a system for the immediate notification of all suspected cases.63 Less than a week later, the World Health Organization (WHO) through its regional counterpart, the Pan American Health Organization (PAHO), issued an epidemiological alert asking countries to report cases of microcephaly and other neurological complications.64 On January 22, 2016, the US Centers for Disease Control and Prevention activated its Emergency Operations Center, followed on February 1, 2016, by a WHO declaration that the cluster of neurological disorders and microcephaly was a “public health emergency of international concern.”65 PAHO Brazil established a “Situation Room” to coordinate information about the Zika virus and its consequences to the country and the world, focusing on international and interagency cooperation, communication and knowledge management, logistical support, and epidemiological analysis.66

61 Government of Brazil, Penal Code, Decree-Law Number 2.848, art. 124, 126.
66 PAHO, “Situation Room – Zika virus infection,” http://www2.paho.org/bras/index.php?option=com_content&view=category&layout=blog&id=1293&Itemid=880 (accessed March 25, 2017). PAHO also operated regionally, developing technical documents and, in June 2016, publishing its strategy for enhancing national capacity to respond to Zika virus epidemic in the Americas. Four objectives orient their activities: detecting introduction of the virus in a timely manner and monitoring the epidemic; reducing the risk posed by high vector density; providing tools and guidance for adequate response management; and developing a regional research agenda. The Strategy was budgeted in USD 17,300,000 until December 2016. According to the last update, on December 8, 2016, PAHO had only raised USD 7.8 million, mainly from the WHO Contingency Fund for Emergencies, DFID, and CDC. Pan American Health Organization (PAHO), “Strategy for enhancing
In late 2015, the Brazilian government launched the National Plan to Combat *Aedes* and Microcephaly with three areas of focus: 1) mobilization and fight against the mosquito; 2) attending the population; and 3) technological development, education, and research.\(^6^7\)

WHO has a Zika Strategic Response Plan, developed in February 2016 and revised in June, which established the basis for coordination and collaboration among WHO and its partners until December 2017.\(^6^8\) The plan calls for four areas of intervention: 1) development of integrated surveillance systems at all levels; 2) prevention of adverse health outcomes; 3) strengthening of health and social systems to provide support to the population affected; and 4) research. WHO also combined efforts with United Nations Population Fund (UNFPA) and UN Women. Within the Situation Room, WHO, UN Women, and UNFPA met with civil society organizations to lead coordination, monitoring, and advocacy for the rights and empowerment of women in the context of Zika.\(^6^9\) As part of this joint effort, UNFPA launched the campaign “*Mais direitos, menos Zika*” (“More rights, less Zika”), engaging youth and women from Bahia—one of the other states hardest hit by Zika—and Pernambuco to mobilize the community in health surveillance actions and provide access to information about the Zika outbreak in order to minimize its impact on rights.\(^7^0\)

In 2016, UNFPA, UN Women, WHO, together with the Brazilian government, organized communication campaigns, including radio programs, reports on television, and flyers and posters addressing women’s rights in the context of Zika.\(^7^1\)

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\(^7^1\) “Actions intensify in response to the Zika virus in Brazil,” *UN Women News Stories*. The public campaign received funds from the Embassy of Canada.
Ten months after calling it an emergency, WHO declared the Zika epidemic was no longer a “public health emergency of international concern.” In explaining the decision, Dr. Margaret Chan, then director-general of WHO, said, “In large parts of the world, the virus is now firmly entrenched. WHO and affected countries need to manage Zika not on an emergency footing, but in the same sustained way we respond to other established epidemic-prone pathogens, like dengue and chikungunya, that ebb and flow in recurring waves of infection.” Some specialists criticized the decision, arguing that governments and donors would slow down their responses, while the general public might misunderstand it as a sign that the outbreak is over.

In May 2017, the Brazilian government announced that the national public health emergency related to the Zika virus had ended, 18 months after first declaring Zika a public health emergency “of national concern.” One of the World Health Organization’s requirements for maintaining a state of emergency is that the event is unusual or unexpected. This no longer is the case in Brazil, as there is now sufficient scientific evidence connecting the Zika virus with congenital neurological impacts. Health officials said that monitoring, surveillance, and efforts to combat mosquito-borne viruses would continue.

State Response to the Zika Epidemic in Pernambuco and Paraíba

The management of the epidemic is a tripartite system between the federal, state, and municipal governments. However, the initial actions to identify and respond to reports of increased cases of microcephaly occurred at the state level. On October 27, 2015, Pernambuco’s Secretariat of Health required the immediate notification of all suspected cases of microcephaly in newborns. Two weeks later, after a high volume of notifications,
the secretariat developed the first clinical and epidemiological protocol on microcephaly, which served as a reference for the national one.\textsuperscript{77} The Pernambuco state protocol set the criteria for identifying microcephaly in newborns in the state, and defined the diagnostic, surveillance, prenatal care, and newborn follow-up services flow. An updated version, released one month later, extended the focus to pregnant women whose fetus is suspected of having microcephaly and pregnant women who have had a rash during pregnancy.\textsuperscript{78} In November 2015, Paraíba’s government also released its own protocol with the same purpose.\textsuperscript{79}

Both protocols present general recommendations for individual action, for example, measures to protect against mosquito bites. Neither state protocol made explicit recommendations to avoid or delay pregnancy, nor provided women with counseling or information about family planning and contraceptive methods.\textsuperscript{80} The most recent versions of the protocols in both states, from December 2015, do not address the risk of sexual transmission of Zika, and present outdated information. As of May 2017, Paraíba’s protocol incorrectly states that the Zika virus is not transmitted through sexual relations.\textsuperscript{81}

In late 2015, the Pernambuco and Paraíba state governments declared a situation of emergency and released their own state plans to fight the diseases transmitted by \textit{Aedes} mosquitoes. Both plans had similar measures, encompassing health assistance, epidemiological and health surveillance, communication, management and monitoring of


\textsuperscript{78} Executive Secretary of Health Surveillance, Ministry of Health, State of Pernambuco, “Clinical and Epidemiological Protocol to investigate the cases of microcephaly in Pernambuco, version no. 2” (“Protocolo clínico e epidemiológico microcefalia, versão no. 2”), 2015, https://media.wix.com/ugd/3293a8_f8bf59781b39477289c57c75e94a40cf.pdf (accessed February 16, 2017).


\textsuperscript{80} Executive Secretary of Health Surveillance, Ministry of Health, State of Pernambuco, “Clinical and Epidemiological Protocol to investigate the cases of microcephaly in Pernambuco, version no. 2,” 2015, p. 27.

the actions implemented, and research. One year later, the government of Pernambuco state renewed for the second time the emergency status and launched a new plan.

Financing for Response to Zika Epidemic

The response to the Zika epidemic required effort at the international, national, state, and municipal level and engaged experts and authorities from various sectors, including health, education, and research. Most of the funding targeted the key pillars of Brazil’s national plan, which focused on mobilization and fighting against the mosquito, providing services to affected populations, and promoting technological development, education, and research.

In March 2016, the federal government announced plans to invest R$649 million (US$203 million) in mosquito eradication efforts, vector control, diagnostic testing, and research. The Ministry of Health also transferred R$2.7 billion (US$840 million) to states and municipalities in 2016 to fund state and municipal health surveillance programs and measures to control *Aedes* mosquitos, together representing an approximated R$800 million (US$250 million) increase in federal disbursements for health surveillance from the prior year.

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The federal government also invested significant resources in ensuring services for affected populations, including commodity acquisition of more Zika and pregnancy tests and repellent for pregnant women enrolled in Bolsa Família, a cash-transfer program for poor families, as well as capital investments in the construction and updating of specialized rehabilitation centers for persons with disabilities.\textsuperscript{86} As of March 2017, 52 new centers were operating, at an estimated cost of R$114 million (US$35.7 million) per year.\textsuperscript{87} According to the Ministry of Health, between December 2015 and January 2017, it expanded the public health system to include 63 new specialized rehabilitation centers, at an annual operating cost of R$128 million.\textsuperscript{88} In 2017 Pernambuco’s Secretariat of Health will expand the rehabilitation services specialized for children with Zika syndrome to its 12 health regions. Currently such services exist in only 10 regions.\textsuperscript{89}

In the area of technological development, education, and research, Brazil’s government announced investments of more than R$250 million (US$78.1 million) in the development of vaccines against Zika and dengue, innovative vector control technologies, and in the research on the prevention, diagnosis, and treatment of Zika.\textsuperscript{90}

Although the national Zika plan does not highlight investment in water or wastewater infrastructure to combat mosquitos, the National Plan on Sanitation, launched in 2013, sets the goals of universal access to water and garbage collection systems in urban areas, and expanding access to wastewater systems to 93 percent of residences in urban areas by


\textsuperscript{88} Email to Human Rights Watch from press office, Ministry of Health, May 31, 2017.


\textsuperscript{90} Ministry of Health, Brazil, “Dengue, Chikungunya e Zika: Saúde destina mais R$ 135 milhões para reabilitação e pesquisas”.
The plan estimated the need for a total of R$508.4 billion (US$158.9 billion) to achieve these objectives.\(^9\) In 2014 and 2015, total investments in water systems and wastewater collection amounted to approximately R$12.2 billion (US$3.8 billion) each year.\(^9\) A recent study published by the National Confederation of Industry (Confederação Nacional da Indústria) found that if the current trend of investments continues, the entire Brazilian population would be fully connected to a wastewater system by 2054.\(^9\) Inadequate water and wastewater infrastructure presents a significant threat to the federal government’s broader efforts to combat *Aedes* mosquitos and the diseases they spread.

States have also invested in eradication efforts. Pernambuco budgeted R$25 million (US$7.8 million) in 2016 to fund a plan to combat all diseases transmitted by *Aedes* mosquitos.\(^9\) Of this, R$5 million (US$1.6 million) was allocated for vector control and materials and personal protective equipment, and another R$5 million (US$1.6 million) was dedicated to awareness campaigns. The remaining R$15 million (US$4.7 million) went to construction of regional centers to attend infants with Zika syndrome.\(^9\) In 2017, Pernambuco’s state government announced investments of R$78 million (US$24.4 million) to combat mosquitos, assist patients with dengue, chikungunya, and Zika, and for research.\(^9\)

To address the very deficient sanitation coverage, Pernambuco entered the largest public-private partnership in Brazil in 2013. With planned total investments of R$4.5 billion (US$1.4 billion) over 35 years, the project aims for universal access to sanitation in 14 municipalities of the metropolitan region of Recife, and Goiana. Within 12 years the

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\(^{92}\) Ibid, p. 170.


\(^{95}\) Pernambuco State Health Department, “PE investirá R$25 milhões contra Aedes aegypti.”.

\(^{96}\) Ibid.

wastewater collection rate was expected to increase from 30 percent to 90 percent, benefiting 3.7 million people.\textsuperscript{98} Three years after the agreement, the rate of wastewater collection has risen to only 32.17 percent, while the companies responsible for the investments face financial problems and construction is behind schedule.\textsuperscript{99} Moreover, total investments in water and wastewater services across the whole state decreased from 2013 to 2015, from R$746 million (US$233 million) to R$550.3 million (US$172 million).\textsuperscript{100} Paraíba witnessed a similar decrease in investments in water and wastewater services, dropping from R$148.4 million (US$46.4 million) in 2013 to R$56 million (US$17.5 million) during the same period.\textsuperscript{101}


II. Findings

In February 2017, the director general of the World Health Organization stated that “Zika revealed fault lines in the world’s collective preparedness. Poor access to family planning services was one. The dismantling of national programmes for mosquito control was another.”\textsuperscript{102} Human Rights Watch found that Brazilian authorities need to take additional steps to address many of these fault lines that existed prior to the Zika outbreak. Our research found gaps in the Brazilian authorities’ response that have distinct harmful impacts on women and girls, and leave the general population vulnerable to continued outbreaks of serious mosquito-borne illnesses in the future.

Instead of planning needed investments in water and sanitation infrastructure to control mosquito breeding, Brazilian authorities have encouraged household-level efforts: namely cleaning water storage containers and eliminating standing water in homes. Women and girls are often the ones responsible for these tasks, but their efforts are burdensome and often futile without attention to structural water and sanitation failures.

Traditional gender roles within society often assign women and girls the primary responsibility for preventing unplanned pregnancy, yet we found that some women and girls did not have access to comprehensive reproductive health information and services through the public health system. Criminal penalties for abortion force pregnant women and girls to turn to clandestine, and often unsafe, procedures to terminate unwanted pregnancies. Pregnant women bear the burden of preventing Zika infection and transmission to the fetus during pregnancy, but we found they often suffer anxiety and uncertainty when they cannot access the information or services they need to protect themselves from the virus. In families raising children affected by the virus, women overwhelmingly take on primary caregiving for babies with Zika syndrome, often without the support that would provide their families the best possible outcomes.

\textsuperscript{102} Chan, “Zika: We Must Be Ready for the Long Haul,” WHO Commentaries.
Human rights should guide Brazil’s efforts moving forward. A human rights-based approach to the Zika outbreak should address gaps in fulfilling the rights to water and sanitation, women’s and girls’ reproductive rights, and the rights of persons with disabilities.

**Mosquito Eradication Requires System-Wide and Household Efforts**

A rights-respecting and sustainable approach to fighting the transmission of the Zika virus would address pervasive problems with the rights to water and sanitation that stymie short-term mosquito eradication efforts. In an emergency phase, vector control focused on the household is key, but it will fail in the long term if systemic problems are not also addressed.

In the emergency phase of a mosquito-borne epidemic, emergency vector control is crucial to a multi-sector response, which includes integrating chemical, mechanical, and biological vector control and individual prevention efforts—essentially backpack, truck, or aerial spraying to kill mosquitoes and larvae and household efforts to eliminate standing water breeding grounds.\(^{103}\) In the long-term, addressing poor water and sanitation infrastructure is needed to achieve lasting vector control.\(^{104}\) To date, this long-term investment in lasting vector control has not been a government priority in response to the Zika epidemic, likely setting Brazil up for years of repeat outbreaks of mosquito-borne illnesses.\(^{105}\) Even medium-term efforts, such as removing aquatic weeds, trimming river and lake vegetation to change sunlight and shade conditions, and maintaining the lining of canals, are not set as a pillar of the response.\(^{106}\)

The World Health Organization, in its guidance on managing pregnancy in the context of Zika virus infection, states, “It is essential to correct the social determinants of viral

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\(^{106}\) Ibid.
illnesses that are transmitted by *Aedes aegypti* mosquitoes at the population level. Strategies to considerably reduce the potential threat of Zika virus infection should therefore include concerted efforts to provide sustainable and equitable access to safe and clean water; consistent application of sanitation and hygiene practices; and appropriate waste management at the community level.”

The Brazilian government has worked to engage households and communities in vector control interventions. Through campaigns and public announcements, the Ministry of Health urged residents to destroy mosquito breeding sites by cleaning and covering water storage containers and eliminating standing water. The federal government combined efforts with state and municipal authorities to intensify eradication efforts. Due to these investments, the share of buildings with mosquito breeding grounds decreased from 3.37 percent in the first cycle of 2016 to 1.91 percent in the last one. Despite progress, the number still exceeds the goal of one percent set by the National Plan to be achieved in June 2016. In addition, initiatives and campaigns involving public schools and civil society organizations raised awareness and mobilized the population to eradicate mosquito breeding sites. UNICEF has also provided assistance to engage municipalities

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108 Brazilian authorities did invest significant resources in the short term. More than 266,000 community health agents (agentes comunitários de saúde), 49,000 endemic disease control agents (agentes de combate às endemias), and 5,000 military officers participated in these efforts. Together, they visited 250 million residences, factories, stores, vacant land and public agencies over the course of seven cycles of inspections in 2016 to identify possible mosquito breeding grounds.


in combatting *Aedes* mosquitos, and trained 2,383 social mobilizers in 707 municipalities, including 771 teenagers.\textsuperscript{112}

Municipalities have also taken steps to eradicate mosquitos.\textsuperscript{113} In late 2015, Recife declared an emergency situation and released an emergency plan to combat the *Aedes aegypti*.\textsuperscript{114} Among other measures, the plan included the hiring of additional 300 environmental health and endemic control agents.\textsuperscript{115} In November 2016, Recife authorities announced the 2017 plan to combat the diseases transmitted by the *Aedes* with several initiatives.\textsuperscript{116} However, investments in sanitation are not part of the plan to eradicate dengue, Zika, and chikungunya, even when there are some investments being made at the local level related to sanitation.\textsuperscript{117} One official in the Pernambuco Secretariat of Health recognized this is not sufficient, saying, “health alone cannot address this issue. So, education, housing, sanitation departments play a role as well.”\textsuperscript{118}

Municipal and state governments have also employed the use of insecticides and larvicides to address mosquito breeding, however a government audit conducted state-by-state over a period between 2014 and 2016 found that more than half of the states and one-fifth of the municipalities investigated did not apply the funds in a timely manner.

\textsuperscript{113} Human Rights Watch interview with Luciana Caroline Albuquerque Bezerra, Executive Secretary of Health Surveillance, State of Pernambuco, Recife, Pernambuco, Brazil, October 20, 2016.
\textsuperscript{119} Human Rights Watch interview with Luciana Caroline Albuquerque Bezerra, Executive Secretary of Health Surveillance, State of Pernambuco, Recife, Pernambuco, Brazil, October 20, 2016.
Auditors also observed expired boxes of insecticides and inadequate conditions of the warehouses in several states. Furthermore, poor management practices, such as inefficient use of the vehicles to spray insecticides, overbilling, lack of planning and inventory control, and failures to distribute insecticides to the municipalities hindered the effort.\textsuperscript{119}

The bulk of the daily effort on mosquito eradication, however, has fallen to individual households to address. The “Cleaning Saturday—do not give a break to the dengue mosquito” campaign, launched in late 2015, called on the population to clean their houses once a week.\textsuperscript{120} One year later, the Ministry of Health released a new campaign with the same approach and different cleaning day (Friday).\textsuperscript{121}

Missing from plans for mosquito eradication was addressing the dismal state of water and wastewater services in many communities. Governments at all levels have not sufficiently addressed longstanding structural failures in water and wastewater systems—limiting the effectiveness of individual household and neighborhood efforts to eradicate mosquitoes, particularly in underserved communities.

The national plan to combat Zika does not address systemic wastewater and sanitation failures contributing to mosquito breeding, which means there are no directed investments in lasting efforts at vector control through the lens of eliminating the risk of Zika and other arboviruses. In October 2016, during the first meeting of a national network of Zika experts, the minister of health affirmed, “Treated water, treated wastewater and garbage collected and treated are fundamental to prevent the dissemination of diseases. We do need to do strong investments in sanitation.”\textsuperscript{122}


Instead a focus on the household shifts the responsibility to make up for poor water and wastewater systems and puts the burden of mosquito eradication efforts on households. Household efforts—namely the elimination of standing water around homes through emptying and scrubbing out containers and covering them, turning them over, or throwing them out—are fundamental to an emergency vector control effort and authorities were correct in emphasizing these efforts immediately. However, household efforts are futile and burdensome in the medium and long-term without national and local investments in lasting vector control through improved water and sanitation. Talita Rodrigues, an advocate in Recife, explained:

State and national health authorities started telling people they had to clean their houses, clean their neighborhoods, don’t leave standing water, but at the same time, there is open water, dirty water, sewage, rainwater, muddy water [in their communities]. So it was really confusing because the state was not looking at its own responsibility [to address problems with water and sanitation], it was transferring responsibility to people to clean their houses.123

Personal responsibility for cleaning households cannot stop mosquito breeding if the water and wastewater infrastructure is insufficient. People who have difficulty accessing water and wastewater services, like many residents of the two cities where Human Rights Watch conducted research for this report—Recife, in Pernambuco state and Campina Grande, in Paraíba state—may be especially vulnerable to mosquito-borne illnesses.124 Indeed, most of the people interviewed for this report told Human Rights Watch that they or another member of their household had been infected with Zika, dengue, or chikungunya in recent years.

Since 2015, Brazil’s economy has suffered a deep recession, with high rates of unemployment and inflation. But long before the recent economic crisis, including in

124 Recife has a history of water-related infections, such as gastro-intestinal diseases, typhoid, and mosquito-borne illnesses that are linked to extreme poverty and a lack of water and sanitation services. “Poverty and Lack of Essential Water and Sanitation Systems are Paramount in the Outbreak of the Zika Virus: Interview with Dr. Esteban Castro, Coordinator of DESAFIO,” European Commission: Research & Innovation, undated, http://ec.europa.eu/research/social-sciences/index.cfm?pg=newspage&item=160225 (accessed February 25, 2017).
times of economic growth, government investments in water and sanitation infrastructure were inadequate.

In 2007, after more than two decades of limited investments in sanitation, congress enacted a new public law addressing sanitation, with implementing regulations adopted in 2010, boosting the sector. An officer at the Ministry of Cities explained that until then, “the legislation was diffuse, which reflects the fact that over decades sanitation was not part of the government’s agenda.” Some states with more resources did invest in the sector, but states in the poorer regions, such as the northeast, worked hard in the period without federal investments to prevent regression in coverage rates. Since 2007, the federal government has increased investment in sanitation. Total investments grew from R$4,238 million in 2007 to R$12,175 million in 2015. Still, the expansion in the provision of sanitation services has been painfully slow. Management and institutional problems—including a simple lack of qualified projects—created bottlenecks in pushing funding out, a foreseeable risk after decades of neglect.

Nevertheless, there has been a small uptick in coverage rates since 2007. The Brazilian population with access to water and wastewater systems increased from 80.9 percent and 42.0 percent in 2007 to 83.3 percent and 50.3 percent in 2015, respectively. In Recife, the share of the population accessing water and wastewater services grew from 72.3 percent and 15.1 percent in 2007 to 76.3 percent and 17.3 percent in 2015. An officer at Paraíba’s sanitation company summarized the context: “Since 2007, they started investing

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126 Human Rights Watch interview with Tiago Raposo, chief of staff at the Secretary of Sanitation, of the Ministry of Health, Brasília, Distrito Federal, Brazil, April 20, 2017.
again, making projects, but not at the necessary speed, and now it has become complicated again because of the Brazilian [economic] situation.”

In the context of the recession, it will be difficult for Brazilian authorities to overcome the deficit in water and wastewater investments and to allocate the resources necessary to sustainably address failing systems.

**Water Storage to Manage Inconsistent Water Supply**

Many households do not have continual access to water without storing water in the home. This is particularly true in communities that rely on clandestine water connections, or in areas that have a problem with supply. In Paraíba state, Campina Grande and neighboring cities have been affected by a serious drought in recent years. The city’s main water source has dropped to dangerously low levels, and intermittent water supply causes many residents to store water in excess of their daily needs in large containers in their homes.

Parts of Pernambuco state have been equally impacted by the drought. According to officials at the state public water company, 30 municipalities’ water systems are in total collapse due to the drought and receive water by truck only. Even one day of water in a month means that the service level does not qualify for trucked water. For example, in Santa Cruz do Capibaribe, access to water is restricted to two days with water and 28 without, but the state water company does not distribute additional water by trucks. “These are used only in cases of total collapse,” according to an official.

Informal neighborhoods in and around Recife often do the same, because they receive intermittent water supply due to clandestine or unreliable connections to the water system. Stored water, if not properly covered and maintained, can create areas for mosquito breeding.

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130 Human Rights Watch interview with Ricardo Benevides, head of the Regulatory Affairs Advisory Department at Cagepa, Paraíba’s sanitation company, João Pessoa, Paraíba, Brazil, April 05, 2017.
131 Human Rights Watch interview with Jose Erivaldo, education secretary, Boqueirão, Paraíba, October 5, 2016.
133 Ibid.
Lindasselva lives in a shack in a slum in Olinda, Pernambuco state. There are no sanitation services and she has access to water from only one tap. Mosquitos can breed and proliferate in stored water, if it is not properly covered and maintained. © 2016 César Muñoz Acebes/Human Rights Watch

For this report, Human Rights Watch asked 60 people visiting health facilities in Pernambuco and Paraíba states and in poor neighborhoods around Recife and Campina Grande about their access to water in the diverse communities where they reside. Only about one-third of them said they had continuous access to water in their homes. The rest said that their water only flowed through the taps two or three days per week, or sometimes less frequently. One official in Recife’s Secretariat of Sanitation confirmed that Passarinhos, one of the communities Human Rights Watch visited, has intermittent access to water. She said, “they say it is one day with water and five without, but we observe that it can be more than five days [without water].”134 While not a representative sample, our

134 Human Rights Watch Interview with Déborah Falcão, official in Recife Secretariat of Sanitation, Recife, Pernambuco, April 17, 2017.
research suggests there are significant barriers to continuous availability of water in homes. A report by the WHO and UN Water confirmed more than one-third of Brazil’s population does not have access to a continuous water supply.\textsuperscript{135}

As a result, most people have no choice but to fill tanks and other containers with water for household use. If not properly covered, those containers become potential mosquito breeding grounds. Clara, a 28-year-old mother of three children living in a poor neighborhood in Recife, explained in detail how a health outreach worker told her to maintain her water storage containers free of larvae. She has a large water tank that collects water when it is running, and then has two large buckets of water that she stores water in for the household to use during the week, “Every Saturday, I empty the water and clean out the buckets, and then I fill it with new water.”\textsuperscript{136}

Where water is scarce or expensive, this type of cleaning regime is not possible. Alícia, a 36-year-old woman in Paraíba who was four months pregnant when she spoke with Human Rights Watch, said she had intermittent access to water at home. “We are afraid of running out of water all at once,” she explained, “[So when the water comes] then we fill up everything. Where I live, there are neighbors with many containers, and it’s full of little [mosquito] larvae, right? One fills up everything one can, so it is complicated because we don’t use all the water and keep it for the following week and, thus, it got worse.”\textsuperscript{137}

Some interviewees in Paraíba said their access to water had decreased since the start of the Zika epidemic, due to the drought and water rationing.\textsuperscript{138} Mirella, 48, told Human Rights Watch, “It’s been a year or more that we have water only three days a week because it’s not raining enough, and the water is not reaching the reservoir.” Mirella said it was difficult for her to care for her four children and elderly mother with an inconsistent water supply: “I have kids at home. They are always getting dirty, and their clothes get dirty. We need water to wash and shower. My mother lives with me as well, and I need water for her too.”\textsuperscript{139}

\textsuperscript{136} Human Rights Watch interview with Clara, Coelhos, Recife, Pernambuco, October 15, 2016.
\textsuperscript{137} Human Rights Watch interview with Alícia, Campina Grande, Paraíba, October 13, 2016.
\textsuperscript{138} Human Rights Watch interviews with Thaís, 17, Campina Grande, Paraíba, October 3, 2016; Karina, 34, Campina Grande, Paraíba, October 6, 2016; Alba, 26, Campina Grande, Paraíba, October 13, 2016.
\textsuperscript{139} Human Rights Watch interview with Mirella, 48, Campina Grande, Paraíba, October 3, 2016.
Natália, a 30-year-old woman in Paraíba who was 34 weeks pregnant when she spoke to Human Rights Watch, said she had access to water every three days. “Due to the rationing, we have to store water, and many don’t store it properly,” she said. She described how her family was affected by a dengue outbreak in her community in early 2016: “In my community, there were many, many cases of dengue.... In my mom’s house, out of four people, my mother, father, and sister all had dengue. Only my niece didn’t have it.... It was an epidemic there.”

**Poor Wastewater Management Systems in Underserved Communities**

Inadequate wastewater management systems, particularly in underserved communities, make household efforts to control the mosquito population futile in the long-term. Many of the marginalized communities Human Rights Watch visited in Recife backed up to open canals or marshes, where garbage and debris led to areas of standing water and stagnation. For many of the communities, their sewage and wastewater flowed directly into these open water sources. According to state public water company officials, today approximately 35 percent of the population in the metropolitan region around Recife has access to wastewater system.

Almost all interviewees said they covered their water storage containers in their homes, but many said there were other sources of standing water in their communities that they could not control. Many of the households living in the highest concentrations of poverty that we visited bordered open water channels or ravines that served to collect untreated wastewater. Mosquitos and their larvae were visible to Human Rights Watch researchers. A 2016 study found that storm drains, among other types of standing water, served as

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140 Human Rights Watch interview with Natália, 30, Campina Grande, Paraíba, October 6, 2016.
142 Human Rights Watch interviews with Samara, 33, Campina Grande, Paraíba, October 6, 2016; Marcia, 29, Recife, Pernambuco, October 20, 2016; Luana, 42, Recife, Pernambuco, October 20, 2016.
143 Human Rights Watch site visit to Coelhos, Recife, Pernambuco, October 15, 2016; Human Rights Watch site visit to Olinda, Recife, Pernambuco, October 18, 2016.
lbral development and adult resting sites for mosquitos that can carry Zika and other viruses, and yet these are often not the focus of eradication efforts.\textsuperscript{144}

In several low-income communities, Human Rights Watch saw untreated sewage flowing into open, uncovered channels, roads, or waterways near communities, creating dirty, standing water—ideal conditions for mosquito breeding. Some interviewees said their flushed toilets went directly into open channels nearby.\textsuperscript{145} A community health worker in a Recife favela with 12,000 residents explained, “All wastewater goes untreated into the

\textsuperscript{144} Igor Adolfo Dexheimer Paploski et al., “Storm drains as larval development and adult resting sites for Aedes aegypti and Aedes albopictus in Salvador, Brazil,” Parasites & Vectors, vol. 9. no. 419 (2016).

\textsuperscript{145} Human Rights Watch interview with Clara, Coelhos, Recife, Pernambuco, October 15, 2016.
river... There is open-air wastewater in the streets.” Clara, who described how she diligently washes and covers her stored water tanks, recognized the limited utility of her efforts because the marsh directly behind the house serves as a mosquito-breeding ground. “I have a flush toilet in the house, and it goes directly into the river. We don’t have any standing water here in the house, but the river is directly behind us.” This is frustrating for her. An environmental health officer recently inspected her water tank and told her “congratulations, keep going!” yet the sewage and solid-waste filled marsh and polluted river behind her remains.

A 19-year-old woman from one underserved community, who sat outside her home with her three-week-old baby while she spoke with Human Rights Watch, said there was often standing water in the street and there were “many, many mosquitos” in her home. She got chikungunya during her pregnancy, but her baby was born healthy.

In another community in Recife, Human Rights Watch researchers walked along uneven, unpaved roads with Rebeca, a 25-year-old woman who was pregnant with twins. She pointed out how sewage flowed directly into the streets in her neighborhood, and dirty, standing water accumulated in areas near her home. “People don’t care how we’re living here,” she said. She had Zika prior to her pregnancy.

Thaís, a 17-year-old girl who gave birth to a baby with Zika syndrome in January 2016, showed Human Rights Watch an open sewage channel near her home in Paraíba state. “We have a lot of mosquitos. The sewage is not covered, and at night it’s full of mosquitos,” she said. When her baby was five months old, Thaís and her whole family, including the baby, got dengue and chikungunya. “No one escaped,” she said. “We could barely walk. Our legs hurt a lot. [We had] fever, rash. I had dengue first and then chikungunya.”

Júlia, 23, lived in the same community and had chikungunya during her most recent pregnancy. She said there was “a lot” of standing water in her community:

147 Human Rights Watch interview with Clara, Coelhos, Recife, Pernambuco, October 15, 2016.
149 Human Rights Watch interview with Débora, 19, Recife, Pernambuco, October 15, 2016.
“The streets have sewage and the channel is open. It’s sewage in the channel.” She explained that health officials visited her home to check her water storage containers for signs of mosquito breeding. “But no one comes to deal with the sewage,” she said.\footnote{Human Rights Watch interview with Júlia, 23, Campina Grande, Paraíba, October 3, 2016.}

**Household Environment Officer Visits Important Line of Defense**

While long-term efforts are needed to address sustainable vector control, even the household efforts of Brazilian authorities have not been sufficient in some places to address vector-control in the home. Many people interviewed by Human Rights Watch did report that health officials visited their homes periodically to check water storage vessels for signs of mosquito breeding, and treat affected water with chemicals to destroy mosquito larvae (larvicides). However, many of them said there was very little, if any, information provided during these visits, suggesting a missed opportunity for educating the public about Zika prevention. Jessica, a 24-year-old woman in Pernambuco state who was eight months pregnant, said, “There’s a sanitation agent who comes to check water in the houses. It’s not to give information, it’s to treat the water…. They put a chemical in the water, but they don’t educate us.”\footnote{Human Rights Watch interview with Jessica, 24, Recife, Pernambuco, October 15, 2016.}

Ana Sophia, a 17-year-old girl in Pernambuco state who was five months pregnant when she spoke to Human Rights Watch, had a similar experience: “They just come, look at the water, and if needed, put medicine in the water.” She believed additional education might lead members of her community to cooperate more fully with the government’s mosquito eradication efforts at the household level. “I think they should inform people,” she said, “because some [of my] neighbors don’t like that they put something in the water because it gets dirty at the bottom of the container. People don’t allow it [the health officials to apply a larvicide] because they don’t like it, but if they knew why it’s important, they might allow it.”\footnote{Human Rights Watch interview with Ana Sophia, 17, Jaboatão dos Guararapes, Pernambuco, October 16, 2016.}

Some women did report speaking to health agents about vector control, but most said the agents told them only about dengue or chikungunya, not Zika, and told them nothing about the need to control mosquito breeding generally. “Health agents came to speak...
about chikungunya and [told us] don’t keep standing water or anything dirty. That’s it, but it was a long time ago,” said Helena, a 34-year-old woman in Recife.155 She thought it might have been in February 2016, eight months before our interview, and shortly after five people in her household contracted chikungunya. Consistent outreach is needed, and the necessity of vector-control to combat multiple threats should be better communicated.

The success of these efforts also relies on a consistent supply of the larvicide and sufficient environmental officers to distribute it to the household level. One municipal environmental surveillance officer in Paraíba told Human Rights Watch that in the months leading up to the epidemic, between May and November 2015, her municipality experienced a shortage in the supply of the larvicide used for vector control due to lack of federal funding. “On average we use 40kg of larvicide per month. There were moments we received only 10kg per month, and moments [between May and November 2015] we didn’t have anything. This shortage happened during a water crisis in the region.”156 She indicated this was consistent in municipalities across the state. A state health surveillance director told Human Rights Watch that employment of environmental officers in some municipalities ended after recent local elections, leaving a temporary gap in services.157

Of most concern is that some people, particularly those living in underserved communities, told Human Rights Watch no one had visited their homes or communities to try to eradicate the mosquito population.158

Impact on Women and Girls

Some women’s rights advocates told Human Rights Watch that the government’s focus on household interventions to limit mosquito breeding had a harmful or stigmatizing effect on women and girls because it creates the impression that they are at fault if they are unable to control the mosquito population. This approach seems to ignore systemic issues related

155 Human Rights Watch interview with Helena, 34, Recife, Pernambuco, October 14, 2016.
156 Human Rights Watch interview with Rossandra Oliveira, environmental surveillance manager at Campina Grande’ Secretary of Health, Campina Grande, Paraíba, Brazil, May 9, 2017.
157 Human Rights Watch interview with Luciana Caroline Albuquerque Bezerra, Executive Secretary of Health Surveillance, State of Pernambuco, Recife, Pernambuco, Brazil, October 20, 2016.
158 Human Rights Watch interviews with Aline, 33, Campina Grande, Pernambuco, October 3, 2016; Clarice, 16, Campina Grande, Paraíba, October 13, 2016; Rebeca, 25, Recife, Pernambuco, October 16, 2016; Erica, 45, Olinda, Pernambuco, October 18, 2016; Karen, 33, Recife, Pernambuco, October 20, 2016.
Traditional gender norms place the burden of household mosquito eradication efforts—cleaning water storage containers and eliminating standing water in homes—on women and girls, who already often take primary responsibility for preventing pregnancy. Paula Viana, executive secretary of Grupo Curumim, a feminist organization in Pernambuco, explained, “There are no government campaigns talking about women’s rights on the Zika issue. It’s all about the mosquito. The message to women is you have to clean your house or don’t get pregnant.” © 2016 Amanda Klasing/Human Rights Watch

to the eradication effort and water and wastewater systems that might undermine household efforts.
rights on the Zika issue. It’s all about the mosquito. The message to women is you have to clean your house or don’t get pregnant.”159

Leaders of a women’s rights group working in an underserved community in Pernambuco state told Human Rights Watch they did research on the impacts of the Zika virus epidemic in their community. They found government communications around the Zika epidemic problematic for women and girls:

What’s being put out [to the public] is that people are responsible for what’s happening. Obviously, we are responsible for disposing of our garbage, but of course the causes of the epidemic are much bigger.160

Vera Barone, a leader of a Uiala Mukaji, a Black women’s organization in Pernambuco, concurs.

Women are being blamed for this crisis. [Women are being told] that they are responsible for not cleaning well enough, not dealing with standing water…. The majority don’t have access to water, so they have to store water, and they are blamed for how they store water. The government doesn’t recognize that the lack of investment in water and sanitation is what leads women to store water. ... In addition, the garbage is not collected properly. The government doesn’t recognize its mistakes. It just blames women.161

One pregnant woman interviewed by Human Rights Watch in Pernambuco state described how she had to be constantly vigilant about standing water and the use of repellent, while coping with the constant anxiety of getting Zika. “I’m being pressured all the time to take all kinds of care with the pregnancy, care for the baby,” she said. “It

159 Human Rights Watch interview with Paula Viana and Sueli Valongueiro, Grupo Curumim, Recife, Pernambuco, Brazil, September 15, 2016.
160 Human Rights Watch interview with Edicléa Santos and Magda Santiago, Grupo Espaço Mulher, Passarinhos, Recife, Pernambuco, Brazil, September 14, 2016.
Neglected and Unprotected 54

affects me a lot. Now, since I’m still at the beginning of the pregnancy and the baby is still developing, I get really frightened.” 162

Reduction Unplanned Pregnancy, Ensure Reproductive Choice

Human Rights Watch found that some women and girls continue to face challenges in accessing basic information and services that would allow them to prevent pregnancy during the outbreak. Further, restrictions on reproductive health services, particularly abortion, can drive women and girls unable to prevent pregnancy but worried about the impact of the virus to seek clandestine and often dangerous methods to terminate pregnancy. Despite the difficulties in preventing unplanned pregnancies, many women and girls interviewed by Human Rights Watch reported struggling to access long-acting or permanent family planning options.

The national protocol on the necessary and appropriate response to the Zika virus included guidance on pre- and post-natal care, and emphasized access to contraception. However, the protocol did not address access to abortion in circumstances in which it would be legal nor did it identify how to overcome barriers in access to contraception among traditionally underserved populations.163

Brazil should take concerted action to reduce unplanned pregnancies by providing women and girls with comprehensive reproductive health information and services, including long-term contraceptive options, and identify and resolve any gaps in distribution or challenges in access. It should also ensure women and girls have reproductive autonomy and access to safe, legal abortion, so they do not have to resort to life-threatening clandestine procedures to terminate unplanned pregnancies they do not want to continue. Excessive legal restrictions on access to abortion hamper a rights-respecting response effort.

Unplanned Pregnancies

A Ministry of Health public advisory on Zika encouraged women and girls to go to their Basic Health Unit to receive an orientation on family planning and contraceptives and to

162 Human Rights Watch interview with Nina, 25, Recife, Pernambuco, October 20, 2016.
choose a contraceptive method to prevent an unplanned pregnancy. It also recommended that women who would like to become pregnant should speak with a health professional before doing so. Yet, the government response did not scale up family planning services, particularly access to long-term contraceptive methods. Due to reports of sexual transmission of the Zika virus, the United Nations Population Fund (UNFPA) executive director, Dr. Babatunde Osotimehin, urged “governments and all other partners to provide information and access to voluntary family planning, including condoms.” Yet, in practice, this does not seem to have been universally part of the response effort encountered by the women and girls interviewed by Human Rights Watch.

One hospital administrator expressed his frustration that this was not a greater priority. “Most pregnancies are unplanned... They have said ‘you shouldn’t get pregnant,’ but didn’t do anything different.” Even when authorities did make family planning a priority, it was after great delay. In November 2016, nearly a year after the start of the public health emergency, Recife authorities did announce strengthening family planning services as part of its 2017 plan to combat the diseases transmitted by Aedes mosquitoes.

A study published in 2017 found that 66 percent of women of child-bearing age in the northeast of Brazil were trying to avoid pregnancy in 2016. But less than one-third of the women and girls Human Rights Watch spoke to about family planning—most of whom we interviewed in health facilities or in communities near Recife and Campina Grande—said their most recent pregnancy was planned. The remainder reported a variety of reasons for an unplanned pregnancy, many hinging on lack of clear and accessible basic information about reproductive health. Although not a representative sample, many of the women who

165 Ibid.
167 Human Rights Watch interview with Dr. Olimpio Barbosa de Moraes Filho, obstetrician/gynecologist and manager of maternity hospital, Recife, Pernambuco, October 14, 2016.
had unplanned pregnancies experienced similar contraceptive failures, often related to lack of information on correct usage.

While most forms of modern contraception have a high success rate under perfect use, many can have increased failure rates when human error is introduced. At least two of the people we spoke to, women ages 34 and 47, reported accidently skipping a pill prior to becoming pregnant. Others reported becoming pregnant while switching to new contraceptive pills or taking antibiotics that interacted with the efficacy of the pill. Several women, including one who has a child with Zika syndrome, reported becoming pregnant while on a low dose contraceptive pill taken while breastfeeding. Some of the women, and one girl, told Human Rights Watch that inconsistencies in the supply of contraceptives to the health centers would cause them to miss doses—either they would be out of pills or injections or the center closed due to strikes.

Several women in their late 30s and early 40s reported being shocked by their pregnancies, some believing themselves to be entering menopause and unable to become pregnant. Veronica, 42 and mother of a child with Zika syndrome, told Human Rights Watch that she thought she was too old to get pregnant. “When I found out, my life collapsed, because he was not planned,” she said.

Overwhelmingly, the women and girls who spoke to Human Rights Watch about unplanned pregnancies described their first reactions as negative—everything from “a bomb going off in

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172 Human Rights Watch interviews with Luna, 25, Recife, Pernambuco, October 17, 2016; Crislene, 27, Recife, Pernambuco, October 20, 2016; and Evelyn, 18, Recife, Pernambuco, October 20, 2016.
173 Human Rights Watch interviews with Laura, 22, Recife, Pernambuco, October 18, 2016; Maria Carolina, Campina Grande, Paraíba, September 12, 2016.
life” to being “disturbed,” “shocked,” “desperate,” or “scared.” 177 Most women who had continued their unplanned pregnancies did not want to discuss details about other options they considered in response to their unplanned pregnancy—including abortion or adoption. Yet, a few told Human Rights Watch that they had considered these other options. One woman, 21, had her first child when she was 16 years old. Pregnant again, unplanned, she told Human Rights Watch, “I knew I had other options, but I never chose them.” 178 Another woman who had an unplanned pregnancy told Human Rights Watch that she “felt broken and sad” after she found out she was pregnant. She considered seeking an abortion, but instead decided to continue the pregnancy and have a tubal ligation performed concurrent to delivery, to prevent any future unwanted pregnancies. 179

Of particular concern is that many mothers who have children with Zika syndrome said they received no post-delivery contraceptive counseling, leaving them without comprehensive information about their options for preventing future pregnancy. 180 A few have since had unplanned pregnancies.

**Clandestine and Unsafe Abortions**

While the women we spoke with were reluctant to discuss abortion in the context of their current pregnancies, studies show that despite criminalization many women and girls in Brazil risk their health and lives to access clandestine abortions. For example, according to a 2015 study, there were as many as 865,000 abortions in 2013 among women and girls ages 15 to 49 in Brazil. 181 More recent research estimates that, by the age of 40, approximately one in five Brazilian women has terminated a pregnancy in her lifetime, and in 2015, approximately 500,000 women had abortions. 182

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178 Human Rights Watch interview, Brazil, October 2016. Name, location, and date withheld for security reasons.
179 Human Rights Watch interview, Brazil, October 2016. Name, location, and date withheld for security reasons.
Very few facilities provide legal abortions. One study estimated only 37 health facilities actively perform legal abortion services in all of Brazil, and that seven states do not have any institutions that offer this service.\(^\text{183}\) Additionally, a very small number of abortions in Brazil occur under legal circumstances. According to one academic study, the 37 active abortion services in Brazil attended 5,075 women seeking legal abortion and performed 2,442 terminations of pregnancy between 2013 and 2015. The study analyzed 1,283 abortions that occurred in five of these services, one from each region in Brazil.\(^\text{184}\) Ninety-four percent of those legal abortions were in cases of rape; 15 percent were provided to girls ages 11 to 14, and five were provided to girls younger than 10.\(^\text{185}\) According to Ministry of Health data provided to Human Rights Watch, 1,667 and 1,678 legal abortions were administered in 2015 and 2016, respectively.\(^\text{186}\) A total of 11,318 legal abortions were conducted between 2010 and 2016.\(^\text{187}\)

The unavailability of and restricted access to legal abortion means the vast majority of abortions that take place are clandestine, and often unsafe, even when they fall within the exceptions provided by law. Human Rights Watch spoke with obstetricians who have provided emergency care for patients who have undergone illegal abortions. One coordinator of an obstetric intensive care unit in Recife recounted extreme cases, including cases where the patient died due to an unsafe abortion. The illegal nature of the abortion makes attending women in crisis difficult:

They are desperate and try anything, and so they use an unsafe method...
We receive many severely sick patients, but it’s not so common to treat them for post-abortion care because people don’t tell the truth. They come with complications but they don’t say what happened... If we knew

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\(^{184}\) Ibid. Some victims of sexual violence are likely denied access to abortion. The study found 14 percent of institutions required rape victims to present a police report in order to access a legal abortion and documented a lack of adequate training on sexual and reproductive rights. The study also showed how some physicians refused to perform abortion on moral or religious grounds, posing additional barriers to women accessing safe and legal abortion.

\(^{185}\) Ibid.


\(^{187}\) Ibid.
something was attempted we could start antibiotics earlier, because the risk of infection is higher.\textsuperscript{188}

According to official data, unsafe abortion is the fourth leading cause of maternal mortality in Brazil. Since 2005, 911 women have died from unsafe abortion, including 69 in 2015, and 48 in 2016.\textsuperscript{189} Approximately 17 percent of the abortion-related deaths between 2011 and 2015 were of adolescent girls and young women between 10 and 19 years old.\textsuperscript{190}

Complications related to unsafe abortion lead to an estimated quarter million emergency room visits each year.\textsuperscript{191} These figures likely vastly under-represent the consequences of unsafe abortion. Since abortion is largely illegal, it is likely that patients who have induced abortion and face complications are afraid to tell medical providers what brought about the complications. This makes data collection on the issue difficult.\textsuperscript{192}

A few women interviewed by Human Rights Watch had experienced or witnessed complications from unsafe abortion. One 23-year-old woman told Human Rights Watch she had taken pills she bought at a pharmacy to terminate a pregnancy when she was raped at age 13. At the time, she did not know that she likely could have accessed abortion legally: “I didn’t have a lot of information. I didn’t know what I could do,” she said. After taking the pills, she experienced heavy bleeding, to the point that her clothing was soaked with blood. “I bled a lot,” she said, describing how scared and unprepared she felt.\textsuperscript{193} Another woman, also 23, said she brought a friend to the hospital with post-abortion complications after she took an abortive substance she had acquired clandestinely. Describing the experience, she said, “She was bleeding a lot, and she fainted. I was with her. I was desperate. I was worried she wouldn’t survive.”\textsuperscript{194}

\begin{footnotes}
\item[188] Human Rights Watch interview with Dra. Leila Katz, emergency obstetrician, Recife, Pernambuco, October 18, 2016.
\item[190] Ibid.
\item[192] Human Rights Watch interview with Dra. Leila Katz, emergency obstetrician, Recife, Pernambuco, October 18, 2016; Human Rights Watch interview with Dr. Olimpio Barbosa de Moraes Filho, obstetrician/gynecologist and manager of maternity hospital, Recife, Pernambuco, October 14, 2016.
\item[193] Human Rights Watch interview, Brazil, October 2016. Name, location, and date withheld for security reasons.
\item[194] Human Rights Watch interview, Brazil, October 2016. Name, location, and date withheld for security reasons.
\end{footnotes}
Those who suffer most from legal restrictions on access to abortion are poor and marginalized women and girls, who may not be able to afford safer procedures, and instead resort to unsafe methods of abortion or feel compelled to carry unwanted pregnancies to term.\textsuperscript{195} One doctor explained, “The truth is in Brazil abortions are done ... Rich people can do it safely. Poor people have to appeal to unsafe methods and they die because of it.”\textsuperscript{196} In the context of criminalization, abusive clandestine providers may take advantage of or even harm the most marginalized women, as illustrated by the tragic case of Jandira dos Santos, which gained international attention. Police suspect dos Santos died from a botched illegal abortion in 2014 and her body was mutilated to obscure her identity.\textsuperscript{197}

The criminalization of abortion also makes women more likely to undergo coerced or unsafe abortion since they cannot freely seek professional medical advice or counselling about their options. One woman told Human Rights Watch about the pressure her partner put on her to seek an abortion, even though it would not be safe. “He forced me to call places to look for pills. It was horrible. It wasn’t what I wanted.”\textsuperscript{198} She was unsuccessful in locating the pills, and continued the pregnancy, which she said was “a relief.”\textsuperscript{199} Not all women are so lucky. An emergency obstetrician told Human Rights Watch that she attended a 26-year-old woman whose boyfriend forced her to undergo an abortion. He took her to a clandestine location, and they put something caustic in her vagina and her uterus ruptured. She lost her uterus and her ovaries, triggering early menopause, and her colon was damaged.\textsuperscript{200}

Legal restrictions on abortion leave women and girls unable to speak openly about their options when they experience unplanned pregnancies. One doctor explained how


\textsuperscript{196} Human Rights Watch interview with Dra. Leila Katz, emergency obstetrician, Recife, Pernambuco, October 18, 2016.


\textsuperscript{198} Human Rights Watch interview, Brazil, October 2016. Name, location, and date withheld for security reasons.

\textsuperscript{199} Ibid.

\textsuperscript{200} Human Rights Watch interview with Dra. Leila Katz, emergency obstetrician, Recife, Pernambuco, October 18, 2016.
decriminalizing abortion could create opportunities for providers to give the comprehensive counseling women and girls need when facing unplanned pregnancies:

The way I see it, the government should legalize and support it [abortion]. That way women can come to the health care system, where there is psychological and medical support. Sometimes all these women need is support. They are alone. If they knew they had other options, like adoption, they might not abort.  

Anxiety and uncertainty around the Zika virus outbreak may have increased demand for illegal abortion in Brazil. A July 2016 study published in *The New England Journal of Medicine* analyzed requests for abortion in 19 Latin American countries received by Women on Web—a nonprofit organization providing abortion medication in countries where safe abortion services are highly restricted—before and after a November 2015 PAHO announcement related to Zika virus risks. The study found a 108 percent increase in abortion requests from Brazil following the PAHO Zika announcement, as compared to a model based on statistical data from prior years.  

The study concluded that with the Zika epidemic in Latin America,

[T]here is both a need for clear information and an increase in requests for abortion that is not currently met by their own healthcare systems. While the WHO response to the Zika epidemic focuses on enhanced surveillance, vector control, communication and guidance, our results show that issuing to women advice that they cannot implement merely precipitates fear and anxiety. Ensuring reproductive autonomy through access to a full range of reproductive choices is currently a missing piece of the public health response to Zika.  

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201 Ibid.


203 Ibid.
The newspaper *Estadão* reported an increase in the number of abortions in Pernambuco state since the emergence of the Zika virus, illustrating its findings with testimonies. A social worker attending pregnant women identified as having complications related to Zika or mosquito-borne viruses told *Estadão* that some of her patients who received an early diagnosis of fetal complications discontinued prenatal care and sought abortions outside the health system. One 28-year-old woman initially happy about her pregnancy, told *Estadão* that she terminated her pregnancy after learning that the fetus had serious neurological problems related to a mosquito-borne virus: “I didn’t mention to anyone [at the prenatal clinic] my intention to abort. I was afraid they would denounce me. I left and disappeared. I looked for a friend and she brought me to a clandestine clinic where she had undergone an abortion last year. My boyfriend gave me the money. Of course I got sad, but I knew this was what I had to do.”

In February 2016, a representative from Pernambuco state introduced a bill in the Chamber of Deputies—the lower house of Brazil’s National Congress—that would increase sentences for women who have abortions due to microcephaly or other fetal anomalies. As of May 2017, the bill had not been brought for a vote.

As a response to the challenges posed by the Zika virus epidemic, in August 2016, the National Association of Public Defenders, with support from the NGO Anis-Institute of Bioethics, filed a petition before the Brazilian Supreme Court to allow pregnant women infected with Zika virus the right to terminate the pregnancy. The petition also called on the Brazilian authorities to provide the full range of benefits to women impacted by the virus, including early and regular screening during pregnancy; a full range of contraceptive methods, particularly long-acting reversible contraceptives; and state benefits if they have

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children affected by the virus. In March, the Socialism and Liberty Party (Partido Socialismo e Liberdade, or PSOL) filed a case calling for the full decriminalization of abortion up to 12 weeks of pregnancy. Human Rights Watch submitted expert briefs in support of both cases in April 2017. As of May 2017, the Supreme Court had not ruled on the petitions.

Problems Accessing Long-Term Family Planning Options

One of the most effective ways to avoid unplanned pregnancies and abortions is to ensure women and girls have access to long-acting reversible contraceptives, such as implants or intrauterine devices (IUDs), or to voluntary sterilization (tubal ligation). Many of the women who spoke to Human Rights Watch expressed a desire to pursue these family planning options, but many of them encountered difficulties. A Secretariat of Health official in Pernambuco state recognized the challenges in accessing IUDs in particular: “We have been working to encourage the use of IUD. ... We have a sufficient amount of IUDs available in Pernambuco. ... The problem lies in the lack of health professionals willing to provide and insert it. Prescribing contraceptive pills is faster and easier. ... Our goal is to provide training encouraging [physicians to provide IUDs].”

One obstetrician-gynecologist providing prenatal care and family planning services to women in Campina Grande explained that she had to refer her patients to the maternity hospital to get IUDs. “We train those who want to get an IUD to go to the maternity hospital,” she said. She said that access to some long-acting contraceptive methods were limited based on municipal residency.

Some women told Human Rights Watch they had never been provided with information about long-acting reversible contraceptive options. For example, Larissa, 28, was four months into a high-risk, unplanned pregnancy when she spoke with Human Rights Watch in October 2016. She had developed thrombosis, a serious blood clot, while taking oral

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208 Human Rights Watch interview with Leticia Katz, head of the Woman Health Care Department at Pernambuco’s Health Secretary, Recife, Pernambuco, Brazil, October 21, 2016.
209 Human Rights Watch interview with Bianca Maria Souza Virgolino Nóbrega, obstetrician, Hospital Pedro I, Campina Grande, Paraíba, Brazil, October 4, 2016.
contraceptive pills. When she tried hormonal injections, she said she felt nauseated and lost hair. “I didn’t adapt well,” she said. Though she had struggled to find a form of contraception that worked for her, no one had ever informed her about longer-term options, like an IUD.210

Others said they could not access longer-acting methods. Júlia, a 23-year-old woman with four children under age 6, said she requested an IUD from the public health system, but was denied. “I tried, but I didn’t get it. The public health system didn’t offer it to me because of my age. The health unit said it’s only allowed to women over 25 years.”211 This is incorrect information, as the minimum age requirement is 20 years of age.212

A hospital administrator told Human Rights Watch that promoting access to longer-acting methods was not a government priority. “Women continue using the same flawed methods ... which are ... less safe than long-term methods like the IUD or implants.”213 He also noted that some government-supported hospitals in more remote municipalities are run by religious institutions that will not provide IUDs to women, further decreasing access to these methods for women far from main urban centers.214

In addition, one official from the Pernambuco Secretariat of Health told Human Rights Watch that aside from the copper IUD, other long-acting reversible contraceptives are not available through the public health system.215 In April 2016, the Ministry of Health decided not to include implants as a choice of contraceptive methods available in the public health system to adolescents between age 15 and 19, citing both the lack of scientific evidence of the effectiveness of this method compared to other available methods and the greater financial impact.216

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213 Human Rights Watch interview with Dr. Olimpio Barbosa de Moraes Filho, obstetrician/gynecologist and manager of maternity hospital, Recife, Pernambuco, October 14, 2016.
214 Ibid.
215 Human Rights Watch interview with Leticia Katz, head of the Woman Health Care Department at Pernambuco’s Health Secretary, Recife, Pernambuco, Brazil, October 21, 2016.
Maria Carolina, a 21-year-old woman in Paraíba state, was prescribed a low-dose contraceptive pill to use while she was breastfeeding her first child, but her provider did not inform her that the pill would not be effective if she stopped breastfeeding, and she became pregnant. When her second child, a girl with Zika syndrome, was born in early 2016, she requested an IUD in the city where she lives, but she was told it would take four months to obtain one. “In my city, they have condoms, sometimes injections, but not the IUD,” she said. “No one speaks about it.” Several women who were raising children with Zika syndrome told Human Rights Watch they were on waitlists to access IUDs through the public health system.

Some women also faced obstacles when trying to access voluntary sterilization. Luna, a 25-year-old woman in Pernambuco, told Human Rights Watch that she “went crazy” and “was desperate” when she became pregnant after her hormonal birth control failed, but she adjusted to the pregnancy. Luna said she requested a tubal ligation after delivering her son, a boy with Zika syndrome, but she faced bureaucratic hurdles. She was told she would need to visit the social assistance office at a specific time to request permission to have a tubal ligation. As a single mother caring for a child with a disability, these additional steps created undue obstacles to accessing the procedure. Her baby was 9 months old when she spoke to Human Rights Watch, but she still had not been able to get the procedure.

Aline, 33, had three children, including a boy with Zika syndrome. When her youngest was one month old, she requested a tubal ligation, but she remained on a waiting list 11 months later. She said she experienced difficult side effects from hormonal contraception, and she was frustrated with having to wait for the procedure. “The moms who have babies with Zika syndrome should have access to get their tubes tied because we can’t have more kids,” she said, explaining that she had to be with her baby 24 hours a day. “I don’t have time to take care of another baby. The moms can’t do it.”

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217 Human Rights Watch interview with Maria Carolina, 21, Campina Grande, Paraíba, September 12, 2016.
221 Human Rights Watch interview with Aline, 33, Campina Grande, Paraíba, October 3, 2016.
Access to Full and Accurate Information and Services for Pregnant Women

More than a year into the epidemic, Human Rights Watch interviewed many pregnant women and girls who did not have access to the information and support they needed to protect themselves from Zika during pregnancy. Brazil’s government should ensure pregnant women and their partners have full and accurate information and services to prevent Zika virus transmission during pregnancy, including related to the sexual transmission of Zika.

Insufficient Information on Zika during Prenatal Clinical Visits

Almost all the women and girls we interviewed who were pregnant or had recently given birth had access to prenatal care, most often through the public health system. During their pregnancies, most of them had regular appointments with medical providers, but most interviewees were not receiving comprehensive information about Zika transmission and prevention during their prenatal visits.

A few women told Human Rights Watch they did not receive any information about the Zika virus during their prenatal care. Most of these women had heard about Zika through media reports and had access to other sources of information, but they described feeling uneasy that they had not received reliable information from medical professionals. For example, Karina, a 34-year-old woman who was 37 weeks pregnant when she spoke with Human Rights Watch in Paraíba state, said no one had given her any information about Zika at all during her prenatal appointments at a hospital serving high-risk patients. “They should have informed us. There are so many doctors and students here. They could take time to give information. I was using repellent because I knew [about Zika], but I didn’t have information on how often to use it.” Karina said she had stopped using repellent near the end of her pregnancy because she stopped hearing about Zika in the news, so she believed the epidemic was over. Jessica, a 24-year-old woman in Pernambuco state who was eight months pregnant when she spoke to Human Rights Watch, said there were signs about Zika posted at the local health center where she had prenatal visits, but she had not

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222 Human Rights Watch interview with Karina, 34, Campina Grande, Paraíba, October 6, 2016.
been given any information by providers. “There should be a conversation,” she said. “I know about Zika, but not everyone knows about it.”

A 2016 survey of more than 3,000 pregnant women in Brazil conducted by the Patrícia Galvão Institute found one-third of respondents had not received any training on Zika virus prevention during their prenatal care.

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There have been efforts to address this gap through the federal and state government protocols. And in July 2016, UNICEF launched the program “Networks of Inclusion” in partnership with governments at the three levels, civil society organizations, PAHO/WHO, the private sector, and other institutions. Taking place in Campina Grande and Recife, the project supports pregnant women, families, and caregivers; trains health, education, and social workers; and promotes integral and integrated care.225

Most pregnant women and girls said their providers gave them basic information about the Zika epidemic and encouraged them to wear repellent, but very few received basic information about the sexual transmission of Zika. Though Zika is transmitted primarily through the bite of an infected mosquito, the virus can also be transmitted through sex.226 Evidence suggests that Zika remains in semen for many months, but public information provided by the Ministry of Health in Brazil does not provide comprehensive information to couples who are pregnant, or wanting to become pregnant, about the risk of sexual transmission. In a list of frequently asked questions about the Zika virus, the Ministry of Health provides contradictory information about the sexual transmission of the virus, stating at one point, “the virus cannot be classified as sexually transmissible,” and stating later, “there is growing evidence that the virus can be sexually transmitted.”227 The first two national protocols developed in response to the epidemic recommend women of reproductive age and pregnant women, along with their family members, take protective measures against mosquito bites, but they did not mention the risk of sexual transmission or recommend pregnant women and their partners use condoms to prevent the sexual

transmission of Zika.\textsuperscript{228} However, the most recent version of the protocol includes a recommendation on the use of condoms during pregnancy.\textsuperscript{229}

Roughly one-third of the women and girls we interviewed who were pregnant or had recently given birth did not know that Zika could be transmitted sexually, and therefore were not taking steps to prevent the sexual transmission of the virus during pregnancy. When Human Rights Watch spoke with 16-year-old Clarice, who was eight months pregnant with her first child, in Paraíba state, she said she had never heard that Zika could be transmitted sexually. “This is the first time I heard about it,” she said, shaking her head in disbelief.\textsuperscript{230}

Others that Human Rights Watch interviewed had learned about the sexual transmission of Zika on the internet or on television, but without comprehensive information, very few were consistently using condoms with their sexual partners to protect themselves.\textsuperscript{231} According to guidance from the World Health Organization, “To prevent potential sexual transmission of Zika virus, sexual partners of pregnant women, living in or returning from areas of ongoing Zika virus transmission, should correctly and consistently use latex condoms for sexual activity for the duration of the pregnancy.”\textsuperscript{232}


\textsuperscript{230} Human Rights Watch interview with Clarice, 16, Campina Grande, Paraíba, October 13, 2016.

\textsuperscript{231} Human Rights Watch interviews with Karina, 34, Campina Grande, Paraíba, October 6, 2016; Samara, 33, Campina Grande, Paraíba, October 6, 2016; Jessica, 24, Recife, Pernambuco, October 15, 2016; Patricia, 21, Recife, Pernambuco, October 15, 2016; Alana, 26, Recife, Pernambuco, October 20, 2016.

Long Waits and Problems Accessing Sonograms and Zika Diagnostic Tests

Some pregnant women and girls interviewed by Human Rights Watch believed, or feared, they had been exposed to Zika, but had difficulty accessing the sonograms and diagnostic tests they needed to find out if their pregnancies could be impacted by the virus.

Many women said there were long waits for sonograms through the public health system, and this contributed to their fear and anxiety around Zika, particularly for those who were unable to go to private providers. For example, Júlia, 23, gave birth to her youngest child in July 2016. She said she was very concerned about Zika during her pregnancy. “I was worried and I felt I couldn’t do anything to prevent something from happening to my baby. I wore pants, long sleeves, repellent. I stayed at home, indoors,” she said, but she lived in a community with standing water and open sewage, where her neighbors had gotten Zika and other mosquito-borne illnesses.

Though she started prenatal care when she was three months pregnant, she was told she could not get a sonogram through the public health system for several months. “I started my prenatal care at three months, but since then, the health unit was not scheduling sonograms. It was booked, so they weren’t scheduling more sonograms, and I didn’t have the means to pay for a private one ... I was very angry and worried for the baby.” When she was four months pregnant, she started to feel pain and went to the emergency room, where they did a sonogram and identified a complication with the fetus. Seven months into the pregnancy, she got chikungunya. But she was not able to get another sonogram through the public health system until the end of her pregnancy. “I had the [second] sonogram at nine months—the week I gave birth.” Thankfully, her baby was born healthy.

In addition, some women and girls told Human Rights Watch they were unable to access specialized second-trimester sonograms that detect differences in fetal development, including microcephaly (fetal anomaly scans, or in Portuguese, ultrassom morfológico), through the public health system. Alana, a 26-year-old woman in Pernambuco state who was six months pregnant with her first child in October 2016, told Human Rights Watch she lived in a neighborhood with poor sanitation and standing water, and that there were many mosquitos in her home. She said she was “enormously” concerned about Zika, but could

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not get a detailed fetal anomaly scan through the public health system, and had to pay to get one done at a private provider. “It caused a lot of worry,” she said. “We really wanted a more detailed ultrasound to see if the baby had any disability, if there was any problem with the baby.”

The World Health Organization’s guidance on pregnancy management in the context of the Zika epidemic recommends, “Regardless of a history of illness consistent with Zika virus infection, all women in areas of ongoing Zika virus transmission should be requested to have a fetal anomaly scan between 18 and 20 weeks or at the earliest possible time if the first visit occurs after 20 weeks.”

Other women had difficulty obtaining Zika tests or test results when they went to medical facilities presenting symptoms of the virus during their pregnancies. Human Rights Watch interviewed Lorena, 22, when she was six months pregnant with her first child. During her first trimester, she got a rash, fever, joint pain, and other symptoms, but when she went to the hospital in her town in Paraíba state, she was told there were no diagnostic tests for Zika available, even though she informed the providers that she was pregnant. “I don’t know which [virus I had] because I didn’t do a blood test,” she said. Up to that point, her sonograms had not shown any anomalies, but Lorena lacked clarity about whether she had been exposed to Zika or another virus.

Vitória, who had just given birth to a healthy baby girl when Human Rights Watch interviewed her in Paraíba state in October 2016, said she went to a hospital with a fever, rash, and other symptoms in the first trimester of her pregnancy. “They did a blood test,” she said, “but they didn’t give us the results.” Vitória said it would have cost R$1,000 for her to pay for a Zika test, so she continued the pregnancy uncertain about what virus she had. “It wasn’t a very easy pregnancy because I didn’t know how the baby would be born. Even the ultrasound doesn’t show real problems that can be there when the baby is born. I

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234 Human Rights Watch interview with Alana, 26, Recife, Pernambuco, October 20, 2016.
cried all throughout the pregnancy. ... It's torture. You have all the doubt and it can only be resolved when the baby is born,” she said.\textsuperscript{237}

A recent survey of more than 3,000 pregnant women in Brazil conducted by the Patrícia Galvão Institute suggests many would like to have greater access to testing and sonograms during their pregnancies. The survey found 90 percent of respondents would like to be tested for Zika during pregnancy if they had access to the exam. In addition, 70 percent of respondents accessing prenatal care through the public health system said they would like to have more ultrasounds.\textsuperscript{238}

The World Health Organization recommends testing for Zika virus infection for “pregnant women presenting with a history of Zika virus disease symptoms or signs.”\textsuperscript{239} The Ministry of Health has allocated resources to state and municipal secretaries for rapid pregnancy tests and to allow women access to second sonograms in the seventh month of pregnancy.\textsuperscript{240} It allocated enough for 2.1 million sonograms to be carried out around the 30th week of pregnancy, claiming this is sufficient to meet demand but not providing a time frame.\textsuperscript{241} Municipal and state authorities confirmed that they had either hired or trained sonographers or gynecologists to perform diagnostic sonograms between 32 and 35 weeks (or at approximately 33 weeks) of pregnancy.\textsuperscript{242}

Zika notification is made based on clinical diagnosis. Health professionals do not have to wait for laboratory results; however, that can mean Zika cases may be diagnosed as dengue or chikungunya.\textsuperscript{243} Laboratory tests can confirm the diagnosis, but during

\textsuperscript{237} Human Rights Watch interview with Vitória, 31, Campina Grande, Paraíba, October 13, 2016.
\textsuperscript{238} Instituto Patrícia Galvão and Locomotiva, “Zika e os Direitos das Mulheres: Mulheres Grávidas em Face da Síndrome Congênita do Zika,” August 2016, pp. 23, 34.
\textsuperscript{239} WHO, “Pregnancy Management in the Context of Zika Virus Infection: Interim Guidance Update.”; also Oladapo et al, “WHO interim guidance on pregnancy management in the context of Zika virus infection,” The Lancet.
\textsuperscript{240} Human Rights Watch interview with Thereza de Lamar, Ministry of Health official, in Brasilia, April 19, 2017.
\textsuperscript{242} Human Rights Watch interview with Eliane Germano, head of the Healthcare Department, Recife Secretariat of Health, April 6, 2017; Human Rights Watch Interview with Leticia Katz, head of the Woman Health Care Department at Pernambuco’s Health Secretary, Recife, Pernambuco, Brazil, October 21, 2016.
\textsuperscript{243} Human Rights Watch interview with Luciana Caroline Albuquerque Bezerra, executive secretary of health surveillance, State of Pernambuco, Recife, Pernambuco, Brazil, October 20, 2016.
epidemics only about 10 percent of suspected cases sent to the labs can be processed, due to resource constraints. Pregnant women are prioritized, according to one Pernambuco Secretariat of Health official.244

**Difficulty following Recommendations for Pregnant Women**

The World Health Organization recommends that pregnant women take several measures to protect themselves from Zika, including “wearing clothes that cover as much of the body as possible,” using mosquito bed nets and screens in homes, and using insect repellents consistently. Few pregnant women who spoke with Human Rights Watch could implement these measures fully, due to both financial and practical constraints. As mosquito repellent is a significant element in Brazil’s response to preventing transmission of Zika during pregnancy, the authorities should provide repellent to women in the public health system to eliminate barriers that prevent pregnant women from using repellent consistently throughout their pregnancy.

Many women told Human Rights Watch they tried to cover up with long pants and long-sleeved shirts, but found it difficult in the high heat of the summer, when *Aedes* mosquitoes are most abundant.245 Only a few women said they had mosquito nets or screens in their homes.

Many pregnant women, particularly those from low-income households, said they did not have the means to purchase mosquito repellent for everyday use during their pregnancy. Interviewees told Human Rights Watch that a bottle of repellent cost around 20 reais (approximately US$6.50) and typically lasted about two weeks. Very few interviewees said health facilities or governments distributed repellent free of charge. As a result, most pregnant women and girls used repellent inconsistently during their pregnancies, and some did not use it at all.

For example, Rebeca, 25, who was four months pregnant with twins when she spoke to Human Rights Watch, cleaned windshields at a stoplight in Recife for work and earned

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other women said they were only able to purchase repellent some of the time. Débora, 19, had given birth to a baby boy three weeks before she spoke with Human Rights Watch in

her community in Recife. She had chikungunya when she was two months pregnant, and her providers told her to wear repellent to protect herself from Zika, but she said she could not get as much as she needed: “Sometimes I didn’t have the money, especially when I wasn’t working. ... I was scared he [the baby] might be born with microcephaly.”

In late 2016, the Ministry of Health announced plans to provide repellent free of charge to nearly 500,000 pregnant women enrolled in the Bolsa Familia cash transfer program, a step that could help expand access to the most vulnerable populations.

Mothers of Children with Zika Syndrome Need Comprehensive Support

Mothers raising children with Zika syndrome told Human Rights Watch they faced obstacles in accessing adequate information and support, both at the time of delivery and as their children grew and developed. The thousands of children born with Zika syndrome in Brazil will need long-term support and care. Their primary caregivers are often women whose lives are profoundly affected by having children with disabilities. Brazil’s government should provide sustained support for the short- and long-term services that will allow children affected by the virus, and their family members, to live with dignity.

Barriers in Accessing Services for Children with Zika Syndrome

The Ministry of Health recommends that children with Zika syndrome from birth to the age of 3 be referred for early stimulation programs offered through the public health system, and receive auditory, visual, motor, cognitive, communicative, and manual stimulation services.

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In some instances, cities such as Recife in Pernambuco and Campina Grande in Paraíba have also provided additional resources to ensure services for children born with Zika syndrome. Recife inaugurated a child development unit in late 2015 focused on children with microcephaly—with pediatricians, pediatric neurologists, occupational and speech therapists, psychologists, and social assistants. Campina Grande, in Paraíba, took the lead in the state by creating a health service specialized in microcephaly, comprising prenatal care, psychological support, and rehabilitation services. It is one of the three cities in Paraíba—the others are João Pessoa and Patos—providing services to children with microcephaly and supporting their families. The municipality also trained the staff of the public day care centers to provide care to these children.

Many children suspected of having Zika syndrome remain without a confirmed diagnosis. In April 2017, there remained 3,236 cases under investigation in Brazil. Without a diagnosis, some children affected by Zika may not have access to early stimulation and specialized rehabilitation services. In March 2016, the federal government grew concerned that confirmation of diagnosis did not quickly follow after suspected cases were first reported, and transferred R$10.9 million (US$3.4 million) to states and municipalities to expedite confirmation of diagnosis in children with suspected Zika syndrome. Some suspected cases seem to have fallen through the cracks. An official in the Secretariat of Health explained the situation in Pernambuco:

[W]e have 238 babies [under investigation] that need to be found ... and diagnosed. Some of them are waiting for [test] results, but the majority are

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254 Human Rights Watch interview with Thereza de Lamare, director of the Programatic and Strategic Actions Department, Ministry of Health, Brasília, Distrito Federal, Brazil, April 19, 2017. See also Ministry of Health and Ministry of Social Development, government of Brazil, Portaria No 405, March 2016.
babies that we could not locate. ... The largest municipalities face the most difficulties locating the babies...

Even a confirmed diagnosis does not guarantee a child is receiving services. As of April 2017, out of the 2,653 confirmed cases, 41.8 percent were receiving early stimulation and 57.4 percent specialized rehabilitation services. A Ministry of Health official told Human Rights Watch that the same child may access both types of services, depending on the degree of severity of the syndrome as manifested. Also, only 51.6 percent of the children with Zika syndrome are accessing standard primary pediatric care, including vaccines.

Most of the mothers interviewed by Human Rights Watch said their children received some, or most, of the services they needed, including physical and occupational therapy and consultations with various specialists. However, some mothers of children affected by the virus said they struggled to access the services their children needed due to the centralization of providers in urban areas, unreliable transportation, and government bureaucracy. Some mothers also struggled to access financial benefits from the government to help cover their children’s needs.

Mothers in both Paraíba and Pernambuco who lived in rural areas or small towns said services for their children were limited outside of urban centers. State health authorities and providers acknowledged that the specialized services for children with Zika syndrome are concentrated in referral centers in big cities. Luciana Albuquerque, executive secretary of health surveillance for the state of Pernambuco, said that initially there were only two institutions, both in Recife, attending children with congenital Zika syndrome. Since then, although the list of institutions has increased to 27 in the whole state, two health regions out of the 12 into which Pernambuco’s territory is divided remain uncovered and still do

255 Human Rights Watch interview with Jadson Galindo, official in the Pernambuco’ Secretariat of Health, Recife, Brazil, April 7, 2017.
257 Human Rights Watch interview with Thereza de Lamare, director of the Programatic and Strategic Actions Department, Ministry of Health, Brasilia, Distrito Federal, Brazil, April 19, 2017.
258 Human Rights Watch identified the caregivers interviewed for this report largely through support groups and medical institutions, and their children with Zika syndrome were already receiving a range of services. It was beyond the scope of our methodology to identify children affected by Zika who were not linked to services. However, many children with Zika syndrome in Brazil may not be receiving the level of services accessed by the families interviewed for this report.
not offer Zika diagnostic and rehabilitation services. Pernambuco’s plan for 2017 is to expand these services to both regions. Dr. Danielle Cruz, a pediatrician in Recife caring for babies with Zika syndrome, described the “lack of professionals available in the countryside of Pernambuco and in the small cities. ... We are trying to provide the best services we can, to use our resources efficiently. Even before the [Zika] crisis, we had a deficit in the provision of pediatric services. We didn’t have enough physical therapists, occupational therapists, and speech therapists specializing in children even before the crisis. Can you imagine how it is now?”

As a result, many mothers said they regularly made long commutes to referral centers in larger cities to access services for their babies. The process was onerous for many of them. Rafaela, 35, lives three hours from the city in Paraíba where her youngest child, a boy with Zika syndrome born in November 2014, receives services. “Here in the center [in Campina Grande] we have all the infrastructure required. But in my town, we don’t have anything,” she told Human Rights Watch. To make it to her son’s appointments, she said she woke up at 3 a.m. and left the house at 4 a.m. Even services that should be available in local health centers may not be consistently administered to children with Zika syndrome—namely standard pediatric care, such as vaccines. Municipal health officials told Human Rights Watch, “Primary care staff are still scared, unsure about how to proceed, they are afraid of vaccinating the babies. Sometimes we observe the vaccination schedule is behind...” As a result, mothers are bringing children from other municipalities to be treated for even basic pediatric care at specialized facilities, or they are having to make multiple trips when one is all that is warranted. One mother explained that her son receives his vaccinations in a local health unit in her community, “However, they don’t

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259 Human Rights Watch interview with Luciana Caroline Albuquerque Bezerra, Executive Secretary of Health Surveillance, State of Pernambuco, Recife, Pernambuco, Brazil, October 20, 2016.
261 Human Rights Watch interview with Dra. Danielle Cruz, pediatrician and family health doctor, Instituto de Medicina Integral Professor Fernando Figueira (IMIP), and Plínio Augusto, doctor, Sistema Único de Saúde, Recife, Pernambuco, Brazil, September 13, 2016.
263 Human Rights Watch interviews with Geuma Marques and Maria Jeanette de Oliveira Silveira, officials at Campina Grande’ Secretary of Health, Campina Grande, Paraíba, Brazil, May 9, 2017.
vaccinate him as they should. He should get four vaccines in one day, but he didn’t. He had to visit the unit four times, once a week.”

For many mothers, the challenge of traveling long distances to access services for their children was compounded by unreliable and disorganized transportation provided by local governments. Many women interviewed by Human Rights Watch said the transportation services they were entitled to were not always available, and accessing them required time and persistence with local bureaucracy, an extra burden many mothers struggled to manage. Rafaela explained, “Last week, I couldn’t come because there was no transportation available. To be here today, I had to fight for two days at the municipal secretariat. Otherwise, we wouldn’t be here.”

Fernanda, a 23-year-old woman with two children, including a boy with Zika syndrome born in December 2015, lives an hour from the city where her son receives treatment. She said she often waited hours for transportation to her son’s appointments, even though she always notified local authorities well in advance. “Two times we arrived here, but late, so we didn’t get the appointment.” She also said she often waited hours to be picked up after her son’s therapy sessions.

“I missed some appointments because we didn’t have transportation,” said Stephanie, 26, who lives an hour outside of the city in Paraíba where her daughter receives services. “There were situations where we waited a long time and the car didn’t come.” Stephanie’s daughter was on a waiting list for a special respiratory therapy offered at a state university. When the university had an appointment available, she was unable to take it because the municipal authority could not provide transportation at the designated time. She was still waiting for the treatment at the time she spoke with Human Rights Watch. Stephanie also said she often waited hours for a ride home after her daughter’s appointments. “I could get home at 3 [p.m.] but I get home at 7 p.m. because they are so disorganized with the transportation.”

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264 Human Rights Watch interview with Aléxia, 20, Campina Grande, Paraíba, Brazil, May 9, 2017.
266 Human Rights Watch interview with Fernanda, 23, Campina Grande, Paraíba, October 6, 2016.
267 Human Rights Watch interview with Stephanie, 26, Campina Grande, Paraíba, October 4, 2016.
When local governments were unable to provide transportation, mothers said they had to scramble to raise funds and organize other transportation. Small municipalities may face many demands in ensuring all people needing specialized services reach referral facilities in urban centers. However, the frequency with which children with Zika syndrome must attend appointments means that resource constraints are more than a minor inconvenience—they can be a weekly or even daily problem. Municipalities should work with mothers of children with Zika syndrome to make even limited transportation services more responsive to their needs.

Some women interviewed by Human Rights Watch also faced challenges getting needed authorizations from local officials to access exams and services that were only available in institutions in larger cities. For example, Antonella, a 34-year-old grandmother and caregiver of a baby with Zika syndrome born in March 2016 in Pernambuco, lives an hour from Recife, where the baby receives specialized service. To schedule appointments at the reference centers in Recife, Antonella or her daughter have to request authorization from the health secretariat in their town. “It’s difficult to schedule appointments because the doctor prescribes it, and we have to go to the health secretariat in [our town],” she said. “We wait months for a free spot.” An ophthalmologist had requested to see Antonella’s granddaughter when she was six months old, but due to the bureaucratic process, the baby could not get an appointment until she was almost one year old. Stephanie, a mother in Paraíba, told Human Rights Watch she had a similar experience. “We should have access to these services in our own town,” she said. “Accessing the exams is a lot of bureaucracy.”

Providers confirmed that many families from rural areas encountered difficulties accessing transportation and authorizations from local officials, at times causing their babies with Zika syndrome to delay treatment or miss appointments.

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269 Human Rights Watch interview with Antonella, 34, Recife, Pernambuco, October 19, 2016
270 Human Rights Watch interview with Stephanie, 26, Campina Grande, Paraíba, October 4, 2016
271 Human Rights Watch interviews with Jeime Leal, physical therapist, Pedro I Hospital, Campina Grande, Paraíba, September 12, 2016; Andréa Sonaira, occupational therapist, Pedro I Hospital, Campina Grande, Paraíba, September 12, 2016; Dra. Danielle Cruz, pediatrician and family health doctor, Instituto de Medicina Integral Professor Fernando Figueira (IMIP), Recife, Pernambuco, Brazil, September 13, 2016; Marina Queiroz, occupational therapist, Juliana Gomes, occupational therapist, and Maria Elisa Farias, physical therapist, Instituto de Medicina Integral Professor Fernando Figueira (IMIP), Recife, Pernambuco, Brazil, October 19, 2016.
Some mothers also had difficulty accessing federal financial benefits for their children with Zika syndrome. Under federal law, any family with an elderly person or a person with a disability is entitled to a monthly salary, equivalent to the federal monthly minimum wage (R$937 or US$297), if total household income is less than one-quarter of the minimum salary per person, per month. There can be only one such benefit payment per family, even if there are multiple family members meeting the criteria. Under a federal law approved in 2016, all children with microcephaly resulting “from diseases transmitted by the Aedes aegypti mosquito” are entitled to access the financial benefit (BPC or Benefício de Prestação Continuada) for a period of three years, if their families meet the criteria.

Many families receiving the financial benefit said it was not sufficient to cover the costs associated with caring for their children with Zika syndrome. Olívia has a baby with microcephaly born in June 2015, and a 6-year-old with autism, but her family receives only one minimum salary. “The minimum wage is nothing,” she said. “It doesn’t meet our needs. Special children need special foods, and even if the government provides us with transportation and health care, the mothers can’t work, can’t study. We don’t have possibilities or normal life.” A father of a child with Zika syndrome, Lucas, said, “I think [the minimum wage salary] is low for him [my son], for his needs, because it is one minimum wage for everything that happens in his life and there is still the family. ... My wife had to quit her job to take care of him.”

A pediatrician caring for 150 children with Zika syndrome in Pernambuco explained that some of her patients have to pay out of pocket for special medications that the public health system does not yet cover. She described how one medication she prescribes to children with Zika syndrome for reflux cost R$100 (US$31) and lasted one month. “The minimum wage is not enough to cover their needs,” she said.

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273 Government of Brazil, Law No. 13,301, art. 18. Various court cases are pending that challenge aspects of this provision, including the stipulation that the benefit will be limited to three years, and the stipulation that the benefit will be granted only after termination of paid maternity leave. The state of Pernambuco created a social benefit specifically for babies with Zika syndrome equivalent to one minimum wage, but state officials we spoke to were not sure how many were receiving the benefit.
“It’s not enough, but it’s what we have,” said Aline, a 33-year-old mother of three, including a baby with Zika syndrome born in Paraíba in September 2015. “We have to manage somehow.”

Impact on Women’s Lives

Among the families interviewed by Human Rights Watch, the primary caregivers of children with Zika syndrome were overwhelmingly the mothers, and the demands of caregiving affected their lives profoundly. Many women and girls said they were unable to continue going to work or school while caring for their babies. Of the 26 mothers of babies with Zika syndrome interviewed for this report, only four said they were able to continue paid work or study after their children were born. While some women may have chosen to discontinue paid work after their children were born anyway, some took parental leave from work with the intent to return after the extent of leave was exhausted. Others were self-employed and had intended to continue with this form of employment, but said they were unable to. Many of the women said it put a financial strain on the family that they could not continue paid work.

Lídia, a 34-year-old mother with five children, calls her youngest son—a boy with Zika syndrome born in Paraíba in December 2015—her “prince.” She explained that she had to stop working after the boy was born: “I was a daily maid at four houses, cleaning the houses, but to take care of his treatment, it’s a lot of things to do. I couldn’t take care of him if I was working.”

Human Rights Watch interviewed Luna, 25, while she sat with her two children waiting for an appointment with a pediatrician. She told Human Rights Watch it was “impossible to reconcile” work and taking care of her son with Zika syndrome, who was born in Pernambuco in December 2015. “He has four to five physical therapy sessions a week,” she said. “No company will grant me that much time off.”

277 Human Rights Watch interviewed 30 women raising children with Zika syndrome for this report.
Similarly, Evelyn, 18, said there was no way for her to return to school after her second
daughter, a baby with microcephaly, was born in Pernambuco in March 2016. “There are
no classes at night,” she said. “I can’t go [to school] during the day because I have to take
care of her.”

Another mother told Human Rights Watch she worked as a receptionist at a lab until her
daughter was born in Pernambuco in October 2015: “When I got back from maternity leave,
I worked for one month, but I had so many appointments for [my daughter]. After one
month, I was fired.”

The few mothers who were able to work while raising children with Zika syndrome said
they negotiated with their employers to get the flexibility they needed, but they struggled
to balance work and caregiving. “The routine is very demanding,” said Ines, a 33-year-old
elementary school teacher and mother of two, including a baby with Zika syndrome born in
March 2016. “There are nights without sleep.”

Some women told Human Rights Watch that caring for their children with Zika syndrome
affected their relationships with their partners and other children. Monica, who often
travels six hours round-trip to appointments with her daughter, worries that she never has
a time to see her 6-year-old daughter. “My aunts care for her. In the beginning it was really
hard.” Jusikelly, a 32-year-old mother of five children, said the birth of her baby with
Zika syndrome in November 2015 made it difficult for her to care for her older children. “My
3-year-old was potty-trained before the baby,” she said. “Now she isn’t.”

In addition, almost all the mothers of children with Zika syndrome interviewed for this
report had experienced what they felt was a form of prejudice or social stigmatization.
Many felt they were not provided with sufficient information or psychological support after
delivery of babies with Zika syndrome to navigate the early weeks of their infants’ lives.

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280 Human Rights Watch interview with Evelyn, 18, Recife, Pernambuco, October 20, 2016.
281 Human Rights Watch interview with Maitê, 29, Recife, Pernambuco, October 17, 2016.
283 Human Rights Watch interview with Monica, IMIP, Recife, Pernambuco, October 18, 2016.
Some of the women and girls interviewed by Human Rights Watch first received the news of an anomaly in their child’s development at the time of delivery, and the experience with how doctors and nurses treated them then had a profound psychosocial impact on many of them. These mothers said the hours and days following the birth of their babies were

285 Women Enabled, an advocacy organization focused on the rights of women and girls with disabilities, recognized a global need for guidance on how to talk about and approach the issue of Zika syndrome from a disability rights perspective. It published important talking points for services providers and advocates in the first few months of the health emergency, imploring both services providers, government and media to use more nuanced language to reduce the risk of social stigma. These talking points can be found here: “Talking Points: Zika, Microcephaly, Women’s Rights, and Disability Rights,” Women

Jusikelly, 32, holds her daughter, a girl with Zika syndrome born in November 2015, in their home in Pernambuco state. She told Human Rights Watch she was unable to continue working when her daughter was born, and her family struggles financially. “I used to work. We had hard times, but not like today.” Jusikelly said the family receives a financial benefit equivalent to the federal monthly minimum wage (R$937 or US$297), but her daughter’s medications cost nearly double the benefit (R$2000). “Where do I find the rest? We pay rent. I have other kids... It is a very big impact. © 2016 César Muñoz Acebes/Human Rights Watch
characterized by tremendous anxiety, uncertainty, and doubt, but many of them were not given full information about their child’s diagnosis or psychological support or counseling to help them cope with difficult news.

Rafaela, a 35-year-old mother of four in Paraíba, said that shortly after she delivered her youngest son in November 2014, the doctor informed her that her baby had microcephaly, but did not tell her what the diagnosis meant. “It’s like they throw you a bomb, and you don’t know how to deactivate it,” she said. “I asked the doctor, ‘What’s going to happen? What will the consequences be?’ The doctor said, ‘if it’s microcephaly he won’t be able to walk, maybe he’ll be blind. He’ll be useless. He won’t be able to do anything.’ I felt rejected, like the worst person in the world. But I also felt very angry. ... I started looking [for information] on the internet with my phone. I read that he wouldn’t be useless. ... I didn’t receive any support or information.”

Most mothers regularly faced insensitive and uninformed questions and comments about their babies from members of the public. The cumulative effect of many small incidents weighed on the mothers. Jacqueline Ioureiro, a psychologist working with mothers of children with Zika syndrome in Paraíba, explained, “At the moment, the mothers and the babies are really close—they are almost inseparable—so it’s hard to say if the prejudice is directed to the baby or to the women, but it is the women who suffer from that prejudice the most. It makes them angry, and tired.”

Fears about the Future

Many mothers we interviewed expressed fears and doubts about what the future would hold for their children with Zika syndrome. They articulated anxiety about how their babies would grow and develop and what they would need, particularly given the scientific uncertainty about the long-term effects of Zika syndrome. Others expressed concerns

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287 Human Rights Watch interview with Jacqueline Ioureiro, psychologist, Pedro I Hospital, Campina Grande, Paraíba, October 13, 2016.
around access to services, education, and the state's ongoing commitment to support families raising children affected by the epidemic.

For example, Mayara, who gave birth to a boy with Zika syndrome in January 2016, said her hope for the future was, “That it will be more inclusive and welcome for babies and kids that will grow up with special needs—the schools, the health system. These issues have been around for a long time.”288 Other mothers explained that they did not know whether their babies would ever be able to walk or talk, so they did not know what kind of long-term care they would need.289

Some mothers expressed concern that the financial benefit for their children would only be provided for three years. “The disability will not disappear when she’s three,” said one mother of a child with Zika syndrome in Paraíba.290

Several mothers said they worried about access to education for their children in the future. Crislene, a 27-year-old mother of a baby with Zika syndrome in Pernambuco, said, “I'm afraid because nowadays we see that they do not have schools prepared to receive special children, not only with microcephaly but with other needs.”291 Luna said she hoped there would be kindergarten classes to accommodate her son when he was ready to begin school. She said she and other mothers needed a place “where we can leave them and be sure that they'll be well-treated, so we can also continue our lives.”292 It was beyond the scope of this report to evaluate whether Brazil’s public education system was prepared to provide inclusive education to children with Zika syndrome as they reach school-going age.

Some providers expressed concerns about their institutions’ long-term financial and operational capacity to serve the needs of children with Zika syndrome. Providers told Human Rights Watch there were too few institutions providing services to children with disabilities, particularly in rural areas, and existing institutions lacked financial resources.

290 Human Rights Watch interview with Stephanie, 26, Campina Grande, Paraíba, October 4, 2016
291 Human Rights Watch interview with Crislene, 27, Recife, Pernambuco, October 20, 2016.
and personnel to serve all the families in need, resulting in long waiting lists and centralization of services in urban areas. One therapist told Human Rights Watch that these problems “existed prior to the Zika epidemic, but they have become worse due to the increasing demand.”

Some providers also worried about the mothers’ ability to maintain the demands of caregiving over the long-term. Providers in Pernambuco told Human Rights Watch how the “hectic routine of sessions and medical appointments” strained both mothers and children, particularly those traveling long distances to access services. Susana, a mother of a boy with Zika syndrome, raised concerns about how she will continue to be able to carry him on the bus, around her neighborhood, and to appointments as he grows. A physical therapist serving children with Zika syndrome in Paraíba said she already observed many mothers exhibiting signs of fatigue: “It makes me worried. If they [the mothers] are tired and exhausted after three months or four months, how will they feel after three years or four years?”

Their fears and concerns are particularly relevant as Brazilian authorities enact fiscal austerity measures that may decrease funding for public health, education, and other services that could help children with Zika syndrome, and their caregivers, have the best possible quality of life in the long-term.

In December 2016, the National Congress approved a constitutional amendment freezing public spending for a period of 20 years, adjusting only for inflation. Before the amendment was passed by Congress, the Oswaldo Cruz Foundation (Fiocruz), a public research and health technology institution, published a letter to the federal government and National Congress warning that the proposed amendment, if approved, “would result in significant harm to people's health and life.” Fiocruz raised particular concerns regarding how the amendment could affect Brazil’s capacity to respond to Zika and other epidemics: “The

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293 Human Rights Watch interview with Marina Queiroz, occupational therapist, Juliana Gomes, occupational therapist, and Maria Elisa Farias, physical therapist, Instituto de Medicina Integral Professor Fernando Figueira (IMIP), Recife, Pernambuco, Brazil, October 19, 2016.
294 Ibid.
295 Human Rights Watch interview with Susana, Recife, Pernambuco, October 17, 2016.
296 Human Rights Watch interview with Jeime Leal, physical therapist, Pedro I Hospital, Campina Grande, Paraíba, September 12, 2016.
question is: how to ensure control of epidemics such as Zika, dengue and chikungunya, including research, assistance, vector control, medicines, and necessary vaccines, with a freeze on resources? In particular, the impact on research, fundamental to new products and new solutions that are already underfunded in our country, will be incalculable, compromising in the long-term the capacity for response and national autonomy.”

The United Nations special rapporteur on extreme poverty and human rights, Philip Alston, called the bill “a radical measure, lacking in all nuance and compassion.” He added, “It will hit the poorest and most vulnerable Brazilians the hardest, will increase inequality levels in an already unequal society, and definitively signals that social rights are a very low priority for Brazil for the next 20 years.” The constitutional amendment took effect in early 2017, and further austerity measure remain under discussion by the government and National Congress.

Engaging Men and Boys in Prevention and Parenting

Much of the public response to the Zika virus epidemic has focused on women, particularly pregnant women and mothers of children with Zika syndrome. A doctor we interviewed in Pernambuco provided a critical analysis of the problem: “It is a patriarchal culture for which the woman is responsible for getting pregnant, and [responsible] if there is a complication.”

Men and boys have an important role in both combatting the spread of the disease and ensuring that children with Zika syndrome have the best access to services and high quality of life. Brazilian authorities at all levels should take steps to ensure that policies aimed at preventing unplanned pregnancy, preventing Zika and other sexually transmitted infections, and caring for children with Zika syndrome do not reinforce harmful, gendered

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299 Human Rights Watch interview with Dr. Olimpio Barbosa de Moraes Filho, obstetrician/gynecologist and manager of maternity hospital, Recife, Pernambuco, October 14, 2016.
notions about men’s and women’s responsibilities within intimate relationships, families, and households.

**Role of Men and Boys in Preventing Zika Transmission and Unplanned Pregnancy**

As described above, Zika can be transmitted sexually, both through vaginal and anal sex. Although it is still uncertain how long the risk of sexual transmission remains after infection, scientists detected Zika virus RNA in men’s semen up to six months after the onset of symptoms, and with a higher viral load than what was found in urine, saliva and plasma samples.

Both men and women interviewed by Human Rights Watch did not know that Zika could be transmitted sexually. “I do not think it is transmitted like that,” said one 40-year-old man interviewed in Pernambuco. “You can get AIDS, syphilis, and gonorrhea, but not Zika.” A 27-year-old man in Pernambuco whose partner was pregnant with their fourth child, said, “I don’t know how Zika is transmitted because people never explained it to us here.” Without comprehensive information on the risks, many interviewees said they or their partners were not consistently using condoms during pregnancy.

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302 Human Rights Watch interview with Marco, 40, Recife, Pernambuco, October 17, 2016.


304 Human Rights Watch interviews with Karina, 34, Campina Grande, Paraíba, October 6, 2016; Samara, 33, Campina Grande, Paraíba, October 6, 2016; Jessica, 24, Recife, Pernambuco, October 15, 2016; Patrícia, 21, Recife, Pernambuco, October 15, 2016; Alana, 26, Recife, Pernambuco, October 20, 2016.
Sueli Valongueiro with Grupo Curumim, a nongovernmental organization that does education and awareness-raising initiatives around Zika and human rights in northeastern Brazil, told Human Rights Watch she was not aware of any initiatives focused on men and preventing the transmission of Zika and other sexually transmitted infections. She said, “We have been working on raising awareness about sexual and reproductive health and rights and the Zika virus with nurses in the primary care network and in hospitals in two municipalities, as well as with women, adolescents, and young people. The testimonies given during our meetings evidence the need for a state intervention that improves the quality of the information [provided] in the [health] services and for the population related to the transmission of the Zika virus through bodily fluids.”

The absence of information and guidance on the role of men in Zika prevention reinforces the idea that women are solely, or primarily, responsible for preventing Zika transmission during pregnancy. As one academic told Human Rights Watch, the narrative around the mothers with children with Zika syndrome has been to focus on their sacrifice, forcing them to maintain this image of saintly women, instead of talking about their rights. In this narrative, fathers are not discussed, or worse, a narrative that men are abandoning their partners and children born with Zika syndrome is perpetuated as absolute.

Brazilian authorities should ensure that public education and individual counseling engage couples and men, and do not single out pregnant women alone to bear the burden of preventing transmission during pregnancy.

Brazilian authorities should also take steps to ensure that men and boys have access to the information and services needed to make fully informed decisions with their partners about family planning options. This was a challenge for some families Human Rights Watch interviewed. One family with a child with Zika syndrome discussed the need for the government to help fathers access vasectomies as a permanent family planning option. Susana, 25-year-old mother of two, was breastfeeding her first child and on a low-dose contraceptive when she became pregnant with her son, who was born with Zika syndrome. At the hospital in Pernambuco, she did not receive counseling on family planning, so she

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306 Human Rights Watch interview with Professor Jorge Lyra, professor and researcher of psychology, Federal University of Pernambuco, Recife, Pernambuco, October 17, 2016.
and her husband went on the internet to research options. The couple decided that a vasectomy was the best option for them, but when he asked for the procedure at the hospital, he was told it had been suspended for budget reasons. Tubal ligations had not been. “My husband wanted to do this, for us. But they said the procedure was suspended. I will get a tubal ligation now, but it would be much easier for him. We don’t have that option, so now I worry a bit. I will have to stay in the hospital overnight, and it might be a tough recovery.” For now, the couple is relying on condoms as their only method of contraception.307

Another mother of a child with Zika syndrome told Human Rights Watch that her husband was unable to access a vasectomy through the public health system in the town in Paraíba where they lived. Through a private provider, they would have had to pay R$3,000 (US$920) for her husband to get the procedure, which was more than the family’s entire monthly income.308 While these experiences do not constitute a pattern of neglect, they do demonstrate that at least in some cases, partners may face difficulties pursuing family planning options that focus on men—namely vasectomies.

**Fathers of Children with Zika Syndrome Need Support for Fuller Participation in Childcare**

Women interviewed for this report and some of their male partners, spoke of the need for the authorities to support fathers as well as mothers in their efforts of rearing children affected by the Zika virus. Providers told Human Rights Watch that fathers needed additional support to actively participate in caregiving. It is challenging for authorities to ensure the provision of services to children with Zika syndrome and to address the logistical challenges faced by caregivers. To the greatest extent possible, however, they should take into consideration how to avoid reinforcing negative gender stereotypes in policies and programs that shift significant burdens for caregiving to women alone.

The few fathers we interviewed who have children with Zika syndrome expressed their desire to support their partners and be involved in caregiving for their children—but logistic and economic challenges made it difficult for them accompany their children to the near daily appointments they had at multiple health facilities. Mothers also consistently reported that they wanted more support from their partners, but similarly that logistics and

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the caregiving challenges related to the children with Zika syndrome made this difficult. Providers told Human Rights Watch that overwhelmingly women and girls brought their babies with Zika syndrome to appointments without the babies' fathers. “It’s rare, the presence of the fathers,” said Jeime Leal, a physical therapist serving babies with Zika syndrome at a hospital in Campina Grande, Paraíba. She said that of the 115 patients she was treating, only four of them were regularly accompanied by their fathers. 309

Yet, when we spoke to some fathers, they expressed a desire to help their partners and a need for greater support so they can participate more in caregiving. One father, Lucas, who was with his wife and child at a physical therapy appointment at a hospital in Recife expressed the need for more outreach to fathers with children with Zika syndrome, “The mothers are warriors. I think the fathers sometimes are absent, but the mothers are always here.” 310 Still, Lucas tries to accompany his wife and child to physical therapy sessions “When I am not working, I come with her…. Whenever I can, I am by her side, because I know how difficult it is.” 311 But, it is difficult for him to play an active role in helping his son access services, “The demand is high, there are a lot children, it always takes a lot of time … we arrive but we don’t know when we will be ready to go home.” 312 With this uncertainty, fathers who are employed have to take the whole day off from work or not go to the physical therapy sessions at all. Lucas is currently able to go because he is unemployed, but he does not feel like he should have to choose between being employed and helping his wife and son.

Human Rights Watch found that for the few fathers we spoke to many factors influence their lower participation in caregiving, some of which could be addressed with more inclusive policies and practices by the Brazilian authorities.

As discussed above, Human Rights Watch found that most mothers were unable to work or study while raising children with Zika syndrome. For some families, this meant that fathers were responsible for earning the sole source of income, making it complicated for men to

309 Human Rights Watch interview with Jeime Leal, physical therapist, Pedro I Hospital, Campina Grande, Paraíba, September 12, 2016.
try to negotiate with their workplaces to get the flexibility they would need to participate more fully in their children’s care. Human Rights Watch interviewed 27-year-old Gustavo, the father of baby with Zika syndrome born in early 2016 in Pernambuco, while he and his wife waited with their baby for an appointment with a doctor. “I am losing a day of work by being here,” he said. He operates machinery for a living, and his family survives solely on his income: “My wife worked before as a waitress, and the plan was for her to come back to work, but she cannot anymore,” he explained. Gustavo came to an agreement with his employer that if he provided documentation from the hospital of the baby’s visit, he could miss work without losing pay. But other fathers did not have this option. Brazil’s labor laws do not protect employees whose children face health problems and require continuous care.

Fathers of Children with Zika Syndrome Need Psychosocial Support

The mothers and fathers of children with Zika syndrome interviewed for this report said they often struggled emotionally and psychologically. Most of the mothers we interviewed had access to some kind of psychological or social support, through a trained professional, a support group, or informal social networks. Some did not think it was sufficient, but for the most part it was available. Some women said they felt their partners did not have adequate access to psychosocial support. The few fathers we interviewed expressed a need for greater support.

Rosalyn, 29, was 36 weeks pregnant when she spoke with Human Rights Watch in Paraíba. She had the Zika virus early in her pregnancy, and her providers had identified several complications in fetal development that they suspected were linked to the virus. The news had been distressing for Rosalyn and her husband. She had been offered psychological support at the institution where she was receiving specialized prenatal care, but she thought her partner needed additional support: “I would like it [psychological support] more for my husband. I have more information. I know more, but I’d also like to have it for him.”

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313 Human Rights Watch interview with Gustavo, Recife, Pernambuco, October 18, 2016.
Fathers described fear and uncertainty when they learned their babies had atypical development. Gustavo, the 27-year-old father of baby with Zika syndrome born in early 2016, said, “It was very difficult at the beginning because I was going to have a special child and had no preparation whatsoever.”\textsuperscript{316} Lucas expressed a similar feeling. “From the moment [we received the diagnosis] we started to analyze everything that will happen to us…. Since we visited the doctor and did the first tests, our struggle started and we continue struggling, every day more.”\textsuperscript{317}

While many of the mothers raising children with Zika syndrome participate in support groups or are in good contact with other mothers, fathers have not connected with each other in the same way. Yet, some seemed interested in a more structured way to speak with other fathers. “Yes, I would be interested” in speaking with other fathers, Lucas told Human Rights Watch. “Sometimes I talk to other fathers while we are waiting at the hospitals, but it is not common. As I am shy, I don’t talk a lot.”\textsuperscript{318}

Some fathers also said they struggled emotionally with the ongoing challenges of raising children with disabilities.\textsuperscript{319} Men interviewed by Human Rights Watch seemed particularly concerned about providing the economic support their families needed, especially when their partners were unable to continue working.

“We are fighting to survive,” said Paulo, a 44-year-old father of six children, including a baby with Zika syndrome born in November 2015. The family had a bakery before their baby was born, but they sold it because Paulo was unable to manage it without his wife’s participation, and she was unable to continue working when the baby was born. “I feel insecure about our lives. If I die, I will leave nothing to my children. I need a psychiatrist. I cry a lot. I feel depressed. It’s related to our financial and psychological situation, to the family.”\textsuperscript{320}

\textsuperscript{316} Human Rights Watch interview with Gustavo, Recife, Pernambuco, October 18, 2016.
\textsuperscript{317} Human Rights Watch interview with Lucas, IMIP, Recife, Pernambuco, October 20, 2016.
\textsuperscript{318} Ibid.
\textsuperscript{319} Human Rights Watch interviews with Lucas, IMIP, Recife, Pernambuco, October 20, 2016, Paulo, 44, Recife, Pernambuco, October 16, 2016, and Gustavo, 27, Recife, Pernambuco, October 18, 2016.
\textsuperscript{320} Human Rights Watch interview with Paulo, 44, Recife, Pernambuco, October 16, 2016.
Gustavo said he had to spend almost his entire monthly salary on medications for his baby with Zika syndrome. “We rely on our family’s help to pay for food, water, and rent... It's very stressful. At the end of the month I do not know how I am going to find the money to pay for his medicines.” Gustavo said the stress affected his relationship with his partner. “When there are 10 reais left at the end of the month, I cannot spend it to have an ice cream with my wife. We used to go out on weekends. Now we basically only take care of him [their baby with Zika syndrome].”

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321 Human Rights Watch interview with Gustavo, 27, Recife, Pernambuco, October 18, 2016.
III. The Brazilian Government’s Human Rights Obligations

Brazil is party to international treaties addressing access to reproductive health services, including safe and legal abortion, the rights to water and sanitation, and other social, economic and cultural rights, and the rights of children and adolescents—including the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Rights of the Child (CRC), and the Protocol of San Salvador. This section examines the Brazilian government’s human rights obligations as they relate to its response to the Zika epidemic, including its failure to meet its obligations related to women’s reproductive rights.

Access to Reproductive Health Services

Sexual and reproductive health and rights and government obligations are addressed in a number of international treaties and other authoritative sources. Article 12 of CEDAW provides that “[s]tates parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.” The CEDAW Committee in its General Recommendation 24 affirmed

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323 In the 1994 Cairo Programme of Action on Population and Development, delegates from governments around the world pledged to eliminate all practices that discriminate against women and to assist women to “establish and realize their rights, including those that relate to reproductive and sexual health.” In the 1995 Beijing Declaration and Platform for Action, delegates from governments around the world recognized that women’s human rights include their right to have control over and decide freely and responsibly on matters related to their sexuality free of coercion, discrimination and violence. See United Nations, Programme of Action of the United Nations International Conference on Population and Development (New York: United Nations Publications, 1994), A/CONF.171/13, 18 October 1994, para. 4.4(c) and United nations, Beijing Declaration and Platform for Action (New York: United Nations Publications, 1995), A/CONF.177/20, 17 October 1995, para. 223.

324 CEDAW, art. 12
The Zika epidemic has put sexual and reproductive health and rights at the epicenter of the crisis. The UN High Commissioner for Human Rights stated that “Upholding human rights is essential to an effective public health response and this requires that governments ensure women, men and adolescents have access to comprehensive and affordable sexual and reproductive health services and information, without discrimination.”

Right to Information

The right to information is set forth in numerous human rights treaties. CEDAW provides that states should provide women “[t]he same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.” The right to information requires the state to provide complete and accurate information necessary for the protection and promotion of rights, including the right to health. Furthermore, the CESCR Committee in its General Comment 14 has stated that the right to health includes the right to health-related education and information, including on sexual and reproductive health. It also noted that “[t]he realization of women’s right to health requires the removal of all barriers interfering with access to health services, education and information, including in the area of sexual and reproductive health.” In its General Comment No. 22, the Committee notes that, “Information accessibility includes the right to seek, receive and disseminate information and ideas concerning sexual and reproductive health issues.... All individuals

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327 ICCPR, art. 19(2); American Convention on Human Rights, art. 13(1). See also Inter-American Court, Claude-Reyes and others Case, Judgment of September 19, 2006 Inter-Am Ct.H.R., Series C. No. 151, para. 264.
328 CEDAW, art. 16(e).
331 Ibid., para. 21.
and groups, including adolescents and youth, have the right to evidence-based information on all aspects of sexual and reproductive health..."\textsuperscript{332}

The CEDAW committee has also noted that, under article 10(h) of CEDAW, women must have access to information about contraceptive measures, sex education and family-planning services in order to make informed decisions.\textsuperscript{333} It has said that specific attention is needed to ensure that adolescent girls “have access to accurate information about their sexual and reproductive health and rights.”\textsuperscript{334} In the same vein, the Committee on the Rights of the Child has also called on states to ensure that children have access to reproductive and sexual education and information, including in schools.\textsuperscript{335} In its General Comment No. 20, the CRC urged states to “adopt or integrate a comprehensive gender-sensitive sexual and reproductive health policy for adolescents, emphasising that unequal access by adolescents to such information and services amounts to discrimination.”\textsuperscript{336}

\textit{Access to Safe and Legal Abortion}

Authoritative interpretations of international law recognize that access to safe and legal abortion services is crucial to women’s exercise of their human rights, in particular rights to equality, life, health, physical integrity, the right to decide on the number and spacing of children, and to be free from cruel, inhuman and degrading treatment.\textsuperscript{337}

Since the mid-1990s, the UN treaty bodies that monitor the implementation of the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention against Torture and Other Cruel, Inhuman,
or Degrading Treatment or Punishment, and the Convention of the Rights of the Child have produced a significant body of jurisprudence regarding abortion in concluding observations concerning close to 100 countries. These treaty bodies have also issued general comments addressing reproductive rights and abortion.

In their commentaries, these bodies have frequently expressed concern about the relationship between restrictive abortion laws, clandestine abortions, and threats to women’s lives, health and well-being. They have repeatedly recommended the review or amendment of punitive and restrictive abortion laws and have urged states parties on multiple occasions to legalize abortion, in particular when a pregnancy is life or health threatening or the result of rape, including incest.

Treaty bodies have made specific recommendations to Brazil in relation to its restrictive abortion laws. The Committee on the Rights of the Child recommended in 2015 that Brazil “[d]ecriminalize abortions in all circumstances and review its legislation with a view to ensuring access to safe abortion and post-abortion care services.” The CEDAW Committee urged Brazil to “[e]xpeditethe review of its legislation criminalizing abortion in order to remove punitive provisions imposed on women.” It also recommended that Brazil “[e]nsure women’s right to safe motherhood and affordable access for all women to adequate emergency obstetric care.”

Rights to Water and to Sanitation

The right to water entitles everyone, without discrimination, “to have access to sufficient, safe, acceptable, physically accessible and affordable water for personal and domestic use.” Various resolutions from the United Nations General Assembly and Human Rights

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338 These numbers are from an analysis of the jurisprudence by Human Rights Watch staff, copy on file at Human Rights Watch.

339 See, for example, Committee on the Rights of the Child, General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24), U.N. Doc. CRC/C/GC/15 (2013), para. 54.

340 UN Committee on the Rights of the Child, Concluding Observations on the Combined Second to Fourth Periodic Reports of Brazil, CRC/C/BRA/CO/2-4, October 30, 2015, para. 60.


Council affirm that the right to safe drinking water is derived from the right to an adequate standard of living.\textsuperscript{344} Brazil has ratified numerous treaties, such as the ICESCR, CEDAW, CRPD, and the CRC, in which the right to an adequate standard of living is enshrined.

The CESCR, in its General Comment 15 on the right to water, stated that “The water supply for each person must be sufficient and continuous for personal and domestic uses.”\textsuperscript{345} The Committee also noted that, “States parties should monitor and combat situations where aquatic ecosystems serve as a habitat for vectors of diseases wherever they pose a risk to human living environments.”\textsuperscript{346}

For its part, the right to sanitation entitles everyone, without discrimination, to “have physical and affordable access to sanitation, in all spheres of life, that is safe, hygienic, secure, and socially and culturally acceptable and that provides privacy and ensures dignity.”\textsuperscript{347} As with the right to water, the right to sanitation is derived from the right to an adequate standard of living.\textsuperscript{348}

The United Nations special rapporteur on the rights to water and sanitation has stated that states should “ensure that the management of human excreta does not negatively impact on human rights.”\textsuperscript{349}

In March 2016, the UN special rapporteur on the human rights to safe drinking water and sanitation stated that “There is a strong link between weak sanitation systems and the current outbreak of the mosquito borne Zika virus, as well as dengue, yellow fever and

\textsuperscript{344} Ibid. See also, UN Human Rights Council resolution 15/9 of September 2010, resolution 16/2 of March 2011, resolution 18/1 of September 2011 and resolution 21/2 of September 2012.


\textsuperscript{348} Ibid. See also, UN Human Rights Council resolution 15/9 of September 2010, resolution 16/2 of March 2011, resolution 18/1 of September 2011 and resolution 21/2 of September 2012.

chikungunya,” and added further that “the most effective way to tackle this problem is to improve the failing services.”

Rights of Persons with Disabilities, Including Support for Their Families and Caregivers

International human rights law addresses the rights of persons with disabilities, including children, and their caregivers. The CRPD recognizes that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children. This includes the right, when possible, to be cared by their parents, as well as the right of children with disabilities not to be separated from their families.

Health services for children with disabilities need to be disability-specific, including early identification and intervention as appropriate and services need to be designed to minimize and prevent further disabilities. Furthermore, children with disabilities should be provided with appropriate habilitation and rehabilitation services “as close as possible to people’s own communities, including in rural areas.” The CRPD also recognizes the right to an adequate standard of living for persons with disabilities and their families, as well as the right to social protection. It says that states parties should “ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counseling, financial assistance and respite care.”

The UN Committee on the Rights of the Child has noted that support to caregivers of children with disabilities should include “[t]he education of parent/s and siblings, not only on the disability and its causes but also on each child’s unique physical and mental requirements; psychological support that is sensitive to the stress and difficulties imposed on families of children with disabilities … material support in the form of special

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351 CRPD Preamble, sec. (r)
352 CRPD, art. 18(2)
353 CRPD, art. 23(3)
354 CRPD, art. 25(c).
355 CRPD, art. 28
allowances as well as consumable supplies and necessary equipment ... deemed necessary for the child with a disability to live a dignified, self-reliant lifestyle, and be fully included in the family and community.”

The Committee on Economic, Social and Cultural Rights has also interpreted the right to social security for persons with disabilities in its General Comments No. 20 and No. 5. It has emphasized the importance of providing adequate income support to persons with disabilities, including permanent disabilities. It has said, “Such support should be provided in a dignified manner and reflect the special needs for assistance and other expenses often associated with disability. The support provided should cover family members and other informal carers.”

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In 2015, the first confirmed cases of Zika virus infection in Brazil put the country at the epicenter of a new epidemic linked to the birth of thousands of children with microcephaly and other health problems, together known as Zika syndrome. The outbreak hit as the country faced its worst economic recession in decades, forcing authorities to make difficult decisions about allocating resources in response.

One year after the government declared Zika a national public health emergency, Human Rights Watch began research in Pernambuco and Paraíba, two of the states hardest hit by the virus. Based on interviews with more than 180 people, Neglected and Unprotected documents how the Zika virus outbreak in Brazil impacted women and girls in distinct ways and aggravated longstanding human rights problems, including inadequate access to water and wastewater systems, disparities in access to health care and information, and restrictions on sexual and reproductive rights. The underlying conditions that allowed the outbreak to escalate in Brazil remain largely unaddressed, leaving the population vulnerable to future epidemics.

Human Rights Watch urges authorities to make long overdue investments in water and sanitation infrastructure to control mosquito breeding and generally improve public health. Authorities should also provide comprehensive reproductive health information and services to women and girls, decriminalize abortion, and ensure children with Zika syndrome have long-term access to services in order to have the best possible quality of life.

(above) Two women walk past a garbage pile near their homes in São Paulo state. Poor garbage collection services can contribute to the proliferation of mosquitoes, which can lay eggs in standing water in objects like used tires and discarded food and beverage containers. © 2016 Lianne Milton/Panos Pictures

(front cover) Raquel, 25, holds her daughter Heloisa in Areia, Paraíba state, Brazil. Raquel gave birth to twin daughters with Zika syndrome in April 2016. “I want to give my best to my daughters,” she said in an interview with Human Rights Watch. © 2017 Ueslei Marcelino/Reuters