Zika in Brazil

women and children at the center of the epidemic
Zika in Brazil: women and children at the center of the epidemic
2017

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Coordination and writing
Debora Diniz is an anthropologist, professor at University of Brasília, Brazil, and researcher at Anis – Institute of Bioethics. She is also a researcher at the Oswaldo Cruz Institute / Fiocruz, Rio de Janeiro. Diniz is the author of the book Zika: from the Brazilian Backlands to Global Threat (Zed Books 2017) and director of the documentary Zika (2016), available on YouTube. In 2017, Diniz was a visiting fellow at New York University School of Law and at the Global Health Justice Partnership at Yale University with a Brazilian Capes scholarship.

Maria Bonita Expedition
Cristiano Guedes is a social worker, professor at University of Brasilia, Brazil, and researcher at Anis – Institute of Bioethics.

Hilca Mariano is a public health nurse from the University Center CESMAC of the Sertão, Brazil.

Martha Ysis is a lawyer and a Master’s candidate in human rights at the Federal University of Paraíba, Brazil and a researcher at Anis – Institute of Bioethics.

Rosineide Lima do Nascimento is a community health agent in Alagoas.

Osmar Kleddson Pinheiro Canuto Rocha is a physician from the Federal University of Alagoas.

Ethical Review
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Photographs
Debora Diniz

Research Assistants
Gabriela Rondon is a lawyer, Master in law, PhD candidate in law at the University of Brasilia, Brazil, and researcher at Anis – Institute of Bioethics.

Martha Ysis is a lawyer, Master’s candidate in human rights at the Federal University of Paraíba, Brazil and a researcher at Anis – Institute of Bioethics.

Luciana Brito is a psychologist, PhD in public health and bioethics, and a volunteer professor at University of Brasilia, Brazil, where she conducts her postdoctoral studies. She is also a researcher at Anis – Institute of Bioethics.

Sinara Gumieri is a lawyer, Master in law, PhD candidate in law at the University of Brasilia, Brazil, and researcher at Anis – Institute of Bioethics.

Transcriptions
Amanda Reis
Cecília Rosal Silva
Júlia Guimarães Brito
Larissa Araújo
Thalita Melchior de Lima
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Governo identifica 399 casos de microcefalia no Nordeste
Ministério da Saúde ainda não sabe a causa do surto de bebês nascendo com má-formação no crânio

Sobe para 108 número de casos de microcefalia em AL

The women and children of the epidemic

Exames confirmam infecção por Zika vírus em dois casos de microcefalia
Informação foi divulgada nesta terça-feira (17). Exames foram realizados no Laboratório da Fiocruz, do Rio de Janeiro.
In February 2016, the World Health Organization (WHO) declared a global emergency situation due to the effects of the Zika virus on pregnancy. The Brazilian northeast was the epicenter of global attention. Daily reports of children born with microcephaly, i.e. with small head circumference, filled the news and frightened pregnant women. Much was said about the epidemic in Brazilian states such as Bahia, Paraíba, and Pernambuco.

The mothers of the epidemic, as the women spokespersons for the effects of Zika on pregnancy came to be known, were from a different area geographically, different from the center-southern part of the country, which is accustomed to talking about itself and its own problems.

they were northeastern women, many of them residents of the backlands or farm workers, distant from the urban centers and TV spotlight

As a northeasterner, I was intrigued by the silence about the women in a small state at the epicenter of the epidemic, Alagoas, squeezed between the giants of the epidemic, Bahia and Pernambuco. These neighboring states were the voices of the science about Zika and, at the same time, the helplessness of the families and their children with small heads. Reference centers for early stimulation were promised, state policies were drawn up, and the mobilization of families began. But Alagoas remained an enigma, even called a “paradox” in terms of understanding about the epidemic. Alagoas is indeed a paradox of inequality – it is the land of Quilombo dos Palmares (one of the most well-known fugitive slave settlements from the 17th century) and Palmeira dos Índios (a municipality of indigenous communities), sugar mills and sugarcane plantations, and high rates of homicide against women, all which contributes to the sense of paradox about the state. But in the context of the epidemic, the meaning was another one.
The policy analyst at the Ministry of Health said that there was a paradox in relation to the intensity of the epidemic in the neighboring states and the mildness with which the Zika virus had affected women in Alagoas. I wondered about whether River São Francisco flowed differently in the state, or if there were more mosquito nets and less larvae breeding in the Backlands of Graciliano Ramos (famous Brazilian novelist who wrote about the rural areas of the northeast), or if there were more sewage and sanitation infrastructure than in Paraíba.

The paradox made no sense: Alagoas is the state with the lowest HDI (Human Development Index) in Brazil – the state’s per capita income is a quarter of the per capita income in the nation’s capital.¹ If the epidemic of Zika mirrors the inequality of Brazilian society, why would Alagoas be immune to the effects of the epidemic? Be it the ecological conditions (climate, mosquito,

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or geography) or the social conditions (population density, sanitation conditions, income inequality, or migratory mobility), there was nothing that suggested a reason for a paradox between Alagoas and Pernambuco.

I have no explanations for why Alagoas presents numbers significantly lower than neighboring state, Paraíba. But as this report demonstrates, the prevalence of children affected by the Zika virus in Alagoas is exactly the same as in Bahia. If something different is occurring in the state – such as poor quality of data, decentralized monitoring of new cases, or a fragile network for caring and accessing reported cases of children to be confirmed or discarded by medical evaluation – it is urgent to know what is happening. This report is a step in that direction.

We began with little pieces already known by the epidemiological surveillance system about Alagoas. In December of 2016, we drove by car through 21 municipalities, more than half of the locations in the state with officially registered cases of children affected by the Zika virus. We named the trip the Maria Bonita Expedition (named after the Brazilian folk
heroine from this region of the country). We visited homes and hospitals, we talked to women and extended families. We listened and have documented here what we describe as a map of the precariousness faced by women and children affected by Zika epidemic in Alagoas, their needs and their rights to a life with dignity.

Who are these women?
If there is still much to be understood about the difference between the numbers in Alagoas and its neighboring states, the lives of the affected women and children herein presented calls for urgent action to protect their rights. They are mostly adolescents or very young women, Black, Brown and Indigenous, with little education, and totally dependent on the country’s increasingly fragile social assistance policies. The numbers, narratives, and images presented here show that if there is indeed a paradox in relation to the epidemic in Alagoas, it is the paradox of the silence surrounding the epidemic’s effects on the lives of families, and women in particular. It is time to prioritize our public concerns and messages – eliminating the mosquito vector is certainly an urgent measure, but protecting the rights and needs of the women and children affected by the epidemic is even more urgent.

There is a humanitarian tragedy in progress and the Brazilian Northeast is the epicenter of global anguish. In 2017, we were preparing for the third wave of women affected by Zika virus during pregnancy and the Brazilian government did little to prioritize them in their protection efforts. To make matters worse, in May 2017, the Brazilian Ministry of Health declared the “end of the emergency situation” for Brazil’s Zika virus epidemic. Falsely, it suggests that there was an “end to the epidemic.” This report is an appeal for women to be put at the center of the epidemic-related protections and care in Brazil. Women and their families are represented here by numbers and via five biographies, an attempt both to demonstrate scale and to facilitate remembrance by those who read us. We hope that readers come to understand the true sense of this humanitarian tragedy and are inspired to take action to guarantee the rights that have been violated by the effects of the epidemic.

Debora Diniz
The Zika virus epidemic
the epicenter in Brazil
Since 2015, the northeast of Brazil has been the global epicenter of the Zika virus epidemic. By April 2017, there had been more than 220,000 reported cases of people with Zika illness. Beyond the magnitude of the epidemic, what was most surprising about Zika was the additional risk of the virus among pregnant women: Zika can alter the development of the fetus, causing the congenital Zika syndrome. The syndrome can cause fetal malformations with diverse neurological effects for the newborn. The most well known sign is microcephaly, that is, the small head circumference in the newborn.

By April 2017, there had been more than 220,000 reported cases of people with Zika illness.

Zika has become a torment for women of reproductive age and particularly for pregnant women. From the onset of monitoring the epidemic, in November 2015, the country has already reported 13,490 newborns suspected of having congenital Zika syndrome. Of these, 2,653 were confirmed as having the syndrome, 105 were classified as probable syndrome cases, and 3,236 still remain under investigation. While Zika fever disease had been known in the medical literature since the 1950s, it was only with the Brazilian epidemic that the effects of the Zika virus on fetal development were identified.

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the most well known sign is microcephaly, that is, the small head circumference in the newborn

In addition to the confirmed and suspected cases, 5,712 cases were discarded and 1,784 were excluded from the Brazilian Ministry of Health notification list. Discarded and excluded are two expressions of epidemiological surveillance that merit specific explanation in light of what we know about the epidemic: discarded cases are those that have undergone medical evaluation and do not have symptoms corresponding with the congenital Zika syndrome; excluded cases are those resulting from typos or double entries. The media and general public still refer to microcephaly as the main risk of the virus in fetuses, but since the declaration of the global emergency situation by the World Health Organization, the more accurate description of the effects of Zika virus on fetuses are “alterations in growth and development possibly related to infection with the Zika virus and other infectious etiologies.”5 In 2016, the medical literature named this set of symptoms the “congenital Zika syndrome”.

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The discarded cases
health policies
In the Epidemiological Report number 10/2016, the Brazilian Ministry of Health adopted the phrase “epidemiological information concerning microcephaly and/or alterations in the central nervous system, provided for by current definitions.” Current definitions is an important category for understanding the analysis we will present in this report: the data about the epidemic follows the scientific knowledge available at the time in terms of medical research about the effects of the Zika virus. Between the publication of a new finding and its incorporation into public health policies, there is a temporal lapse, in addition to difficulties related to the implementation of new practices by actors in state and municipal health systems. Even with the temporal mismatch between science and health policies, policy documents are subject to constant changes in the ways in which a suspected case is reported, which ends up hampering the comparisons of numbers since the beginning of the epidemic in 2015.

Data about the epidemic follows the scientific knowledge available at the time in terms of medical research about the effects of the Zika virus

The main clinical criteria used for the public health alert were newborns with the sign of microcephaly, that is, with a smaller head circumference than expected for their gestational age. At the beginning of the epidemic, the head circumference considered normal was 33 cm for a newborn over 37 weeks; later the measurement was reduced to 32 cm. In 2016, the criterion changed to the InterGrowth table, in an attempt by WHO to establish international standardization (30.24 cm for girls, 30.54 cm for boys).

There is an explanation for these changes in the definition of suspected cases: these are attempts to align the epidemiological surveillance system with new scientific findings. On the other hand, cases discarded under provisional criteria from the first two years of the epidemic may be cases that are currently “unknown” in the care network. We now know that there are cases of babies who are born without any indication of microcephaly and yet who may have been affected by congenital Zika syndrome, presenting symptoms in later months.7

An important barrier to the implementation of new surveillance methodology for the effects of the epidemic is the difficulty of measuring head circumference with the proper precision, given that Brazil does not have tools that measure up to two decimal places and the inclusion criteria are not easily interpreted except by professionals familiar with orthopedics or neurology. On the other hand, there is an expectation that cases with fetal alterations identified by ultrasound diagnosis might be reported as suspected cases. However, the public health services only guarantee one ultrasound during pregnancy, and

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the recommendation is to perform it in early stages of pregnancy. The Zika effects, however, are more visible at later stages of pregnancy, which makes the ultrasound a limited criterion for inclusion.\(^8\) The new surveillance methodology faces even greater barriers in Alagoas, given the state’s high rates of delayed prenatal care, and the highest rates of adolescent pregnancy in Brazil, according to the National Information System on Live Births (SINASC 2015).\(^9\)

\(^8\) In addition to the medical reasons for the early ultrasound, there are affective reasons for women. In Brazil, it is common to name fetuses – thus, the family refers to the unborn fetus by a name. To name the fetus, it is necessary to know the sex of the fetus, which creates lots of anticipation in relation to the first ultrasound. The MS / SAS Directive n. 650, of October 5, 2011, Annex II recommends only one (1) obstetric ultrasound for pregnant women considered to be low risk. Available at: [http://bvsms.saude.gov.br/bvs/saudelegis/sas/2011/prt0650_05_10_2011.html](http://bvsms.saude.gov.br/bvs/saudelegis/sas/2011/prt0650_05_10_2011.html)

Cities in Alagoas equipped to conduct computerized tomography (CT)

To add to the complexity of the situation, with the emergency of the epidemic, federal and state governments developed different policy responses for identifying suspected cases.

Pernambuco was the epicenter of the Zika epidemic and the first state to develop its own medical protocol. Other states did the same with different impacts on the support for children and their families. The protocol for Alagoas is such an example. Published in January 2016, among the diagnostic requirements for including a reported child in the care protocol, in addition to the examinations and evaluations provided for in the national policy, Alagoas demands the computerized tomography (CT) with a result suggestive of Zika infection alterations to include a newborn in the Zika health care protocol.10

The national policy recommends that some imaging be done: a transfontanellar ultrasound (a simpler and more accessible image) and/

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or the computerized tomography. In Alagoas, only two public hospitals have a tomography machine (Hospital Geral de Maceió and Hospital de Arapiraca), with a months-long wait for the exam. Alagoas’ Zika health policy holds that a newborn with microcephaly would have priority access to the tomographic examination, but access is not actually immediate. This means that a newborn is notified and then awaits the examination to determine if he/she should be included in the care for children with congenital Zika syndrome. Inclusion or subsequent exclusion is based on this imaging report.

just as important as caring for the confirmed cases is understanding why Alagoas has twice as many discarded cases per live births as Bahia

There is, therefore, a second barrier in the inclusion / exclusion of the child in public care: the radiologist’s report has to indicate an abnormality typical of Zika. There is a presumption that at the time of the epidemic there would be a diversity of medical specialties updated in terms of the “current definitions” about the effects of Zika virus on the neurological development of a newborn. Finally, given the current knowledge about the effects of the Zika virus on the development of the fetus, it would be most prudent to review all cases “discarded” on the basis of radiological reports at the beginning of epidemic, in order to evaluate whether they would be probable or confirmed cases according to other specialties such as audiology or ophthalmology. In other words, just as important as

12 Alagoas decreed an emergency situation for the Zika virus epidemic on December 11, 2015.
Discarded cases

A comparative table of prevalence by live births between Alagoas and its neighbors will be presented below.

The term “midwives” refers to nursing technicians or nurses who perform delivery in a hospital setting. In Brazil, the authorization and qualification of other professionals to assist in delivery was an achievement for the reduction of morbidity and mortality associated with childbirth in remote regions where there are no doctors to assist with delivery. Therefore the issue here is not to impose restrictions on childbirth with midwives, but to ensure adequate forms, means, and resources of communication and training in terms of health policies related to the Zika epidemic considering the profile of midwives, who are also responsible for measuring the head circumference of the newborn, a central symptom for reporting suspected cases.
Methodology

numbers, images, and narratives
Alagoas is the first state to have a comprehensive case study like what we present here – we have traveled over 800 km, visited 21 municipalities, interviewed 54 women with children who were confirmed or discarded by the current criteria at the time of birth or during pediatric care. The field research was conducted in December 2016 and, at the time, the Ministry of Health reported that Alagoas had 86 cases of children confirmed as having the Zika congenital syndrome and 51 cases under investigation.15

The active search for families occurred via different sources, such as: official epidemiological surveillance records (municipal, state, and federal), WhatsApp groups of mothers of children with the congenital Zika syndrome, health teams at reference centers, and community contacts.

The official state records did not provide names for the women, only the municipalities where their cases were recorded. With this geographical data, we arrived at the municipality and headed to the local motorcycle-taxi stand to ask about “children with the mosquito problem” or “small-head children”, expressions used by the community and which will be analyzed here as part of the narratives of stigma and the accommodation of communities to the new disease.16

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16 To find the discarded cases, we would arrive with as many clues as possible, including for example date of birth and municipality, from official documents and community informants, and we would initiate our search at the local motor-taxi stand.
In parallel to the data collection carried out during the expedition in Alagoas, we consulted the Ministry of Health and the Ministry of Social and Agrarian Development for data about the reported cases of congenital Zika syndrome in Alagoas. The consultation was carried out in accordance with the procedures of the Law on Access to Information (LAI) – Law 12.527/2011), which regulates the right to obtain access to public information. For all cases reported in the state between 2015 and April 2017, we requested disaggregated information on the women’s races, ages, and towns of residence. We also asked about the coverage of the cash transfer benefit (Continuous Cash Benefit, BPC) for children affected by the Zika virus. The information provided by the government demonstrates the fragility of Brazilian official data.

Of the 54 women, we reclassified 5 cases as notification errors and as a result they are not included in this report. To exclude those cases, we considered the following criteria:

a. Diagnostic imaging of the newborn with a normal result;

b. Newborn head circumference of 33cm at birth;

c. The woman did not have any record or recollection of Zika illness during pregnancy;

d. The child has shown no symptoms of developmental delay or neurological disorders according to reports from pediatric care; and

e. Diagnostic confirmation by more than one medical professional that this is not a case of congenital Zika syndrome.

17 These cases would be classified as “excluded” by the epidemiological surveillance system if they were reviewed in pediatric care.

18 Here we adopted the head circumference criterion for a reported case from the beginning of the epidemic, that is, we adopted a broad criterion to exclude children from the final sample. There was only one registered case of head circumference of 29cm in the records that we received from the Ministry of Health – however, when we located the family in the town of the notification, we identified that it had been a recording error: the data said that it had been a twin pregnancy, and there was only one child; the record indicated 29cm at birth, but the measurement performed 24 hours after delivery indicated 33cm; all the pediatric care and specialized records and exams indicated normal development.
This report therefore refers to 49 families, of which 39 (80%) have children with alterations compatible with the congenital Zika syndrome and 10 (20%) are under investigation for Zika or other congenital alterations without conclusive diagnosis or were discarded according to the criteria adopted in Alagoas.

The families interviewed were not based on sampling criteria, because our identification efforts were cumulative, based on different records or community reports. If we cross-reference the official data from the Ministry of Health and the individuals we interviewed, this study represents 45% of the confirmed cases in Alagoas, and 20% of the cases under investigation. Because it is an epidemic with environmental characteristics, the diversification of localities was a factor that we prioritized in the active search for families: of the 40 total municipalities in Alagoas with confirmed cases, this study covered 52% (n = 21). It is through the combination of the two sampling frames – people and locations – that the data portray the effects of the epidemic in the state.

The 10 children without definitive diagnosis were included in the analysis for three reasons:

a. The criteria established by the Ministry of Health to discard cases as possible cases of congenital Zika syndrome were not fulfilled, i.e. they might be discarded cases based on known criteria for the effects of Zika at the time of diagnosis, but the
children were not subsequently evaluated according to the new and more adequate criteria;\textsuperscript{19}

b. The examinations for diagnosis of other congenital alterations, particularly the TORCH infections, were only carried out in three children and in one of them the test was reactive for toxoplasmosis, but the images suggested different patterns of congenital infection;\textsuperscript{20}

c. The children presented multiple symptoms and signs of some congenital syndrome, with similar if not identical living and care needs as children with confirmed diagnosis of congenital Zika syndrome.

Each woman was interviewed individually and the vast majority was interviewed in their homes (only 4 women were interviewed at the Dr. Hélvio Auto University hospital, the state’s reference center for the treatment of tropical diseases, on the day of their child’s consultation). The interviews had two methodological components. The first was a narrative-oriented conversation, guided by topics that explored demographic elements, reproductive health (family planning, childbirth, and post-partum), access to social benefits (income transfer, medications, and transportation), as well as experiences of discrimination and infant care. The second component was a semi-structured questionnaire that repeated questions from the open interview, but with emphasis on demographic elements (age, race, income, number of children, education, etc.), urbanization and habitation (sewage, garbage collection, type of housing etc.), and access to health services and early stimulation for the child.

The women were previously consulted about their agreement to participate in the research. All were asked to sign the informed consent form, and the research protocol was approved by the research ethics

\textsuperscript{19} The 10 children had CT scans. The results are generically described as “altered result, with other alterations” in the radiologist’s report. None of them had a transfontanellar ultrasound, fundoscopy, or magnetic resonance imaging. Only one of them had an ultrasound examination in the first trimester with a normal result.

\textsuperscript{20} TORCH infection is an acronym for the most common diseases that cause intrauterine infections: Toxoplasmosis, Other (syphilis, varicella-zoster, parvovirus B19), Rubella, Cytomegalovirus (CMV), and Herpes infections. In April 2017, the reference laboratory for Alagoas (LACEN) informed the state’s Secretary of Health that it did not have the reagents to test for the infectious diseases with mandatory reporting.
committee of the University of Brasilia. The interviews were long, about one hour each, and one-third of the women participated in more than one interview. Only in three families did men participate in the interviews and in a timid way, more as observers than narrators. The visits were also documented via photographs, and some of those photographs illustrate this report.

We decided not to anonymize or change the names of the people whose biographies we present here. Our reasons are simple and touch on the ethical subtleties of a narrative about the epidemic:

a. An epidemic transforms the survival of people into numbers, and to represent them via statistics is at the same time a strength and weakness – the strength is in showing that the cases presented here as “violations or rights” are not isolated cases or individualized events; the weakness, however, is that numbers are distant from the realities of life because we do not know the faces of those affected by the epidemic;

b. The national and international news intensely exhibited the families of Zika, particularly those of the states of Paraíba and of Pernambuco. There were few narratives that presented the families of Alagoas.

For these reasons, we chose to show and identify the families here. Of the 49 families, we selected five biographies of families with children with congenital Zika syndrome, considering that these five stories embody the experiences of violations of rights. The five families were consulted and agreed to their participation in the report. The contributions from the digital communities were all made anonymous and the images of these digital contributions were altered to not allow identification. By digital communities, we are referring to WhatsApp.

The interviews facilitated a fluid narrative, and in some cases the women shared intimate and perhaps risky experiences given the context of moral vigilance over reproductive practices. In Brazil, there is no legal protection of confidentiality for research; the only profession with the right to confidentiality of sources is journalism. The research coordinator has certification as a professional journalist, which guarantees the women the right of source confidentiality. Even with this protection, we chose not to obtain signed consent in cases of more sensitive narratives, maintaining oral consent without any biographical identification.
to interactions by text, voice, photograph or video, that is, the virtual
groups formed by families with children affected by the Zika virus
epidemic. Our research team participates in five groups, some local,
some state-level, others national-level. Two groups are comprised of
families from Alagoas. All of the participants were informed that we
were active in the groups for the purpose of research and information
exchange, but because conversations via WhatsApp are always more
fluid and spontaneous than in formal interviews, we opted together
to ensure anonymity.

There are no differences between the group of women with children
with confirmed congenital Zika syndrome and those women with
children whose cases of Zika or other congenital infections are still
under investigation, and so the data on all women and children will be
presented together. In addition, the universe of families is too limited
(n = 49) to draw comparisons that would allow us to explore differences
between groups of women. Initially, we disaggregated the two groups
by age, race, schooling, access to social benefits, and the results were
similar. There is a homogeneous profile of precariousness in terms of
the lives of the women in this region who are affected by infectious or
tropical diseases with a risk of vertical transmission.

After transcribing the interviews and tabulating the questionnaires,
some responses were confirmed by telephone, in particular those that
demanded very precise data, such as age at first pregnancy, access
to social benefits (in particular the BPC, the cash transfer benefit) or
health services for children.22 Data on family income have been collected,
but are tenuous for reasons already known from previous studies,
particularly that families might not disclose information about income
for fear of losing social benefits or because of embarrassment related to
these questions in contexts of extreme poverty. The women participants
from the virtual communities were the first to read this report and their
comments were considered in revisions.

22 The Continuous Cash Benefit (BPC) is an income transfer benefit from the Ministry of Social
Development equivalent to a monthly minimum wage for every person with a disability whose family
income is less than ¼ of the minimum wage per person (i.e, US$ 80 per person/month).
Finally, at the end of each interview, families were informed about social benefits available for their specific needs. Their doubts related to child health, sexual and reproductive health, or access to social welfare assistance were clarified. The presence of a social worker, a lawyer, a physician, a nurse, and a community health agent in the research team allowed us to identify the main needs of the families, which informed the development of an access to information booklet that was subsequently distributed via the WhatsApp groups in Alagoas.
Alagoas
the face of inequality
Alagoas

12/31/2016

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

CASES
- CONFIRMED
- UNDER INVESTIGATION
- DISCARDED

CASES/10,000 LIVE BIRTHS
2015 to 2016

PB  78
PE  75
BA  35
AL  35

ACCUMULATED PREVALENCE OF CHILDREN AFFECTED BY ZIKA
2015 to 2016

PB  21%
PE  14%
BA  9%
AL  ?
According to the Epidemiological Bulletin number 6/2017, as of December 31, 2016, Alagoas had 371 reported cases, 3.6% of the national total, of which 86 cases were confirmed, 51 cases were still under investigation, and 234 cases were discarded.\(^2\)

The state of Alagoas has a smaller cumulative prevalence of children affected by Zika when compared to neighboring states of Pernambuco (21%), Bahia (14%), or Paraíba (9%). The data presented by the Ministry of Health, however, does not present reported cases in proportion to the number of live births for the period: it compares absolute data between the states, which, given the unequal populations of the states, should be considered with caution when the objective is to understand the effects of the epidemic.

**Why would the epidemic have been intense in neighboring states and mild in Alagoas?**

When we plot the number of cases reported in each state by the total number of live births in the same period, we found that Alagoas has a rate of 35 cases per 10,000 live births, similar to that of Bahia, with 35/10,000, while Paraíba has 78/10,000 and Pernambuco has 75/10,000, in the accumulated period of 2015 and 2016.\(^2\) Alagoas, however, is known as one of the “paradox” states of the Zika virus epidemic in the Brazilian northeast – Why would the epidemic have been intense in neighboring states and mild in Alagoas?


\(^2\) Because the Ministry of Health data for notifications of newborns and children with altered growth and development possibly related to Zika virus infection and other infectious etiologies are cumulative for 2015 and 2016, we multiplied by two the number of live births according to SINASC 2015. Because the rate may have changed if the epidemic impacted the state’s fertility rates, we extrapolated the data for 2015.
Our thesis is that there are no ecological or social reasons for a paradox between neighboring states at the epicenter of Zika epidemic. It was only necessary to regroup the data about the magnitude of the epidemic by number of live births and the epidemiological picture of Alagoas was transformed, approximating itself to the picture in states that received greater political or media attention during the epidemic. Bahia is considered one of the country’s epicenters, while Alagoas is the “paradox.”

**it is the map of survival in the extreme precariousness of life**

Certainly, there is still an important difference between the rates of Alagoas, Paraíba, and Pernambuco, neighboring states with very similar ecological and social characteristics. Research is needed about the quality of reporting and the methods for entering a reported case into the health system (such as, for example, the impact of the requirement of a CT report for a case to be considered confirmed or excluded) to determine if there is in fact a difference between Alagoas and its neighboring states, Paraíba and Pernambuco. Only then could the paradox hypothesis be addressed – it is necessary to first eliminate the variables related to quality of health care, and the forms and efficiency of the epidemiological system in Alagoas.

In this report, we have taken another path to demonstrate the face of the epidemic in Alagoas – we followed the available records to present a portrayal of survival. The women of the Zika epidemic in Alagoas are the face of the inequality of Brazilian society: they are young, Black, Brown, and Indigenous, most experienced their first pregnancy during adolescence, and they have little education and are out of work. Almost all of them are fully dependent on public health system, social assistance policies, and education to care for themselves and their children affected by congenital Zika syndrome. Across all the indicators that we will present, the women of the Zika epidemic are worse off than women of the same profile in Alagoas and in a much worse situation than women in the rest of the country. It is a portrayal of survival in the face of the extreme precariousness of life.
Age, race, and income

About half of the women became pregnant and were affected by the epidemic while they were still in adolescence (51%, n = 25), and their ages ranged from 14 to 19 years. Taking into account previous children, 75% (n = 37) of the women interviewed had become pregnant during adolescence. Six of them got pregnant before the age of 15 and the children affected or under investigation for Zika syndrome are the second, sixth, or seventh child. This means that three out of every four women caring for a child affected by or under investigation for Zika congenital syndrome became pregnant in adolescence. According to data from the National Information System on Live Births (SINASC 2015), this number is about three times greater than the state’s rate of teenage pregnancy (26%), which is already among the highest in the country, and around four times the national rate (18%).

The women of the Zika epidemic in Alagoas are the face of the inequality of Brazilian society: they are young, Black, Brown, and Indigenous, most experienced their first pregnancy during adolescence, and they have little education and are out of work

In addition to being very young, the majority of the women are Black and Brown (80%, n = 39), and at a rate higher than the state’s racial distribution (72%), and much higher than the national rate (53%), according to the...

25 According to information from the Ministry of Health, obtained via the Law on Access to Information (LAI), 28% of the women of reported cases in Alagoas between 2015 and April 2017 were between the ages of 13 and 19 at the time of notification (this universe of women, with the exception of those excluded, was 418, of which 118 were adolescents). The Ministry of Health does not have information about the age of first pregnancy of women affected by Zika.

Brazilian National Household Survey (PNAD 2015).\(^{27}\) Alagoas is the land of quilombolas (residents of communities descended from fugitive African slaves) and of indigenous nations; one of the women was of the Xucuru-Cariri people, near the city of Palmeira dos Índios. Cross-referencing youth and race, other aspects of the precariousness of life were distinct in the women’s profiles: 6% (\(n = 3\)) of the women were illiterate (according to PNAD 2015, the national rate is 1.4% if we consider the same age range of women without schooling, between 24 and 29 years). For almost half of the adolescents, the level of formal schooling was very low: 52% (\(n = 13\)) had not completed elementary school (the national rate of adolescents between 17 and 19 years old with incomplete elementary education is less than 15%, according to PNAD 2015).

\(^{27}\) According to information from the Ministry of Health, obtained via LAI, for 37% of the women with reported cases, there was no response for the question on race. With such a loss in data, there is no reliability in the official numbers about race.
Reproductive health

For reasons that we do not know, the initiation of prenatal care for women of all ages was very late: 32% (n = 16) started prenatal care after the first trimester and one of the women did not have any health care during her pregnancy. There are two understandings for this low and late entry into care, and both precede the emergence of the Zika virus epidemic in Alagoas. The first is that women are not aware of their pregnancy until they feel physical signs, in particular a growing belly. The second reason is related to the barriers of accessing prenatal services: many of the municipalities we visited are remote and even when there are services offered at health facilities near to women’s homes, there were recurrent reports of inadequate staffing of professionals or supplies.

Associated with these structural reasons preceding the Zika virus epidemic, one finding deserves to be investigated considering the narratives of women with children affected at different moments of the epidemic. We interviewed women of the first peak of the outbreak (2015) and the second peak (2016) – for the former, the Zika virus did not pose an additional risk to pregnancy or the health of their future children, since for decades these women had already lived with the main transmitting mosquito, Aedes aegypti, in addition to other similar tropical viruses, such as Dengue or Chikungunya. The Zika virus was not part of their concerns or prenatal care, and most of them only knew about the risk of vertical transmission at the time of delivery when the newborn was diagnosed with microcephaly.

There is widespread lack of knowledge or rejection of information about the risk of sexual transmission of the Zika virus. The main counter-evidence is testimonial: “In my house, I had Zika and my husband did not have it”. The transformation of Zika from a mosquito disease to a sexually transmitted disease requires a reconfiguration of the dominant

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28 The study by Adriana Moura and Maria Júlia Correia showed that only 34% of pregnant women who used the Maceió municipal service between June 2007 and May 2012 had their first prenatal care before the 12th week of gestation (MOURA, Adriana Avila, MELLO, Maria Júlia G, CORREIA, Jailson B. Prevalence of syphilis, human immunodeficiency virus, hepatitis B virus, and human T-lymphotropic Virus infections and coinfections during prenatal screening in an urban Northeastern Brazilian population. International Journal of Infectious Diseases. 39; 10-15. 2015).
narratives in public opinion, but especially in the ways that community accountability is framed in relation to the country’s epidemic – in 2014, one of the campaign slogans of the Ministry of Health was “The danger increased. And so did everyone’s responsibility too”; in 2015, “If the Dengue mosquito can kill, it cannot be born. He now also transmits Chikungunya and Zika.” In 2016, the then president declared that “A mosquito is not stronger than an entire country.”

the Zika virus was not part of their concerns or prenatal care, and most of them only knew about the risk of vertical transmission at the time of delivery when the newborn was diagnosed with microcephaly

About half of the women did not use any methods to avoid a new pregnancy, although none of them indicated current plans to have another child (43%, n = 21). Among those who used some method (57%, n = 28), the pill was the most common method (70%, n = 19), but adherence was irregular, and the second most common method was injection (15%, n = 4). Only one woman used the IUD. Among adolescents, 52% (n = 13) did not use any methods and none of them reported wanting another child at the time. None of the adolescents used condoms or an IUD. Those who did not use any methods were not able to respond at the time of the interview whether or not they were pregnant.

For the women of the second peak of the epidemic, even with rudimentary information about the forms of transmission of the Zika virus, there was current knowledge about the risk for the development of the fetus, be it through the media or through contact with other women in the
community with children with congenital Zika syndrome. In this second group of women, initiation of and adhesion to prenatal care was even later compared to women of the first peak, a piece of data whose meaning we cannot dissociate from other layers of precariousness in the women’s lives, such as young age, low schooling, or transportation difficulties.

However, when we asked the women of the second peak their reasons for delaying prenatal care or not performing the sole ultrasonography considered routine in the public health system, given that these women also reported having symptoms of Zika during pregnancy, the responses were evasive, in general, related to the lack of time because of having to care for other children, or difficulties with transportation. A few, however, described experiences of mental suffering during prenatal care due to the lack of resources for treatment if the fetus were affected by the Zika virus – knowing in advance “would bring bad luck,” they explained. Those who had experienced another pregnancy after the birth of the child with the congenital Zika syndrome oscillated between two extremes of anguish: either an impetus to undergo sequential and unnecessary imaging tests, or to distance themselves from prenatal care.

The anxiety for additional examinations was not observed as a practice among the women interviewed in Alagoas, particularly given the financial hardship of paying for private ultrasounds. But in the WhatsApp national communities, where there are women of different social classes, this was a recurrent discussion. During the interviews, we found women in evident mental suffering. Some of them, such as the case of a young couple from Dois Riachos, described in detail their suffering and asked for psychological assistance for the woman and the family. Two adolescents reported having thought about suicide and one of them reported getting close to an attempt.
Abandonment of care

The superstition about bad luck should not be viewed as a result of the low schooling of the women interviewed, but as a form of resilience in the face of the medical narrative about the irreversible nature of the effects of Zika and, mainly, as an attempt to normalize the uncontrollable effects of the epidemic.29 Women reproduce the medical information about the meaning of newborn microcephaly in two contradictory ways, but both full of meaning for survival when understood in the context of maternity as a woman’s family duty and the abandonment of care in social policies.

When asked “What does he have that makes him go to the doctor?”, the first answer is: “He has microcephaly.” Microcephaly is the physical embodiment, the diagnosis, and the epidemic – the word is much more than its current use by medicine. In the course of explaining “microcephaly” there are layers that emerge in the narratives. The first is the normalization of the child, because microcephaly is just “a small head”. It is common to say “he is normal, he only has the microcephaly problem,” which could falsely suggest a misunderstanding about the meaning of the medical diagnosis. "Normal" and microcephaly is a pair that needs to be joined to confront public curiosity about the child with the “mosquito problem”. Describing the child as normal is a way of rejecting the degrading questions heard by almost all the women, either at the time of childbirth or on their return home – whether they were going to abandon their child, whether they would be able to love the child, or whether they thought the child beautiful.

To affirm the normality of the child is to ground mothering in affection and care, to reject public suspicion about child abandonment, or about liability for having gotten sick from Zika during pregnancy. To have microcephaly and to be normal is thus a complex affective and moral construct about

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29 A family interviewed in Areia Branca, in the state’s backlands, had a child who had been reported and discarded by the sole criterion of diagnostic imaging, the report stating “images not compatible with Zika”. In addition to receiving no assistance during the prenatal period, there was no TORCH test after delivery, when head circumference was 25 cm. The mother was a young woman and had 7 children. In the total absence of assistance, we accompanied her to a traditional medicine session in the community with a faith healer. The family did not receive BPC, and their monthly income was around US$100 from Bolsa Familia (cash benefit transfer for families with children under 17).
LETTER FROM A SPECIAL CHILD

Mom, when I look at you I feel so safe
In the comfort of your arms I find peace.
In your sweet voice, I lose my fear.
Mom, I know that my routine is not easy.
Sometimes I see you are tired, but you do not let yourself be defeated.
Sometimes I see you cry, even though I do not understand your worries.
Sometimes I see you upset when something goes wrong with my treatment.
You fight for and struggle for me.
When I cry you try to understand and when you cannot you become frustrated out of fear that I am in pain.
Mom, do not worry, you have been the best mom in the world.
We will not always win the battles, but we will fight them all together.
I love you, in you I found the strength to continue living.

FOR YOU "SPECIAL" MOM

That we continue to cherish the small gestures, the small things, the small moments, the small victories of our children, the "small big" things that life has shown us
That we do not become hardened, despite all of the setbacks
That we do not become shaken, despite all of the obstacles
That we continue to believe in people of good faith, despite the masks that fall from some people, sooner or later.
That we do not lose the instinct to laugh, even in the midst of pain
That we do not lose our faith, despite all of the sadness and the disillusionment surrounding all of our lives
That we have the wisdom to thank God, for all of the difficulties we encounter on our path, because it is in those moments of difficulties and weaknesses that we grow and transform into what we are today
We know that without struggle there is no victory
And without effort there is no compensation
We have learned and lived that where there is faith, there are miracles
Our children are living proof of God’s miracle in our lives
That we continue to believe always!!!
I don’t know if I should laugh or cry...the government says that we can live on my husband’s minimum salary and denies the benefit for my daughter! And so I ask how can I buy medications, pay for gas with the 151 reais that is left?! OUTRAGED, ANGRY

**MONTHLY BILLS**
Cash benefit transfer: 880
Rent: -250
Milk: -120
Diapers: -100
Water bill: -35
Energy bill: -211
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Remaining = 151,00

I’m the mother of [redacted] who is a year and two months, I discovered [redacted]’s micro during pregnancy, it scared me at the time, we are never prepared to receive that type of news, it was a complicated pregnancy.

I had Zika in the first months of my pregnancy I had chicken pox immediately after I discovered the micro, but the only fear that I had was of losing my baby, since [redacted] was born alive, it has been a daily struggle, as they say I kill a lion a day to survive,

There are many more questions and lots of curiosity, I try to take in stride the clueless questions that people without information ask, but sometimes because we are tired we end up saying things that we shouldn’t, and we agree that some people need to be told to give us some space, that they are bothering us, the difficulties are immense, people who do not respect, not only on the street but also on the bus where we do not have the time, and it is a general disrespect, we need everything, but we cannot complain about anything, we mothers we live behind the facade the government puts up, that everything is ok, everything is great.
maternity and inclusion, care, and struggle against discrimination: the definitive identity of the child is that of “special child.” Not one of the women described their child as having a disability, deficiency, or even as sick, but as a “special child.” There are frequently message chains in the WhatsApp communities about the meaning of being the mother of a special child: there are also concurrent constructions about the meaning of being a special mother, shaped by the sanctified motherhood of Christian religious discourse.

From many women, we heard about daily occurrences that could be described as public expressions of discrimination against or rejection of the child, but few of them actually used the language of rights to describe situations, for example, of people removing the hat from babies’ heads or touching them. There is a subtle layer here of cultural language and accommodation to humiliation: not all curiosity is understood as offensive, because the sharing of life experiences in the community is intense. To name the curiosity as discrimination is a slow process for many women – it was in the digital communities where we began to hear about these incidents of curiosity as discrimination.

This is a shift in language that begins to appear as the child grows, and the signs of congenital Zika syndrome become more evident. The pairing of microcephaly and normal is more easily accommodated for infants than for children who have reached the age of two. With the growth of the children and the greater difficulties of transportation or access to health services, women come to experience the curiosity as an abject feeling of discrimination against the Zika syndrome. It was in the digital spaces that we accompanied suffering from traumatic events, serious offenses such as texts of hate and spurning against the child.
Social assistance and labor

It was exactly the pairing of microcephaly and normal that led us to use caution in the questions about access to the Continuous Cash Benefit (BPC). Most families did not receive BPC (63%, n = 31), but not because their family income was higher than the ceiling to receive the benefit or because they did not have material needs. We did not visit any house, not even in the capital, which we could describe as even lower middle class in terms of its standards of urbanization or habitability.30

The requirements of medical and social service documents were considered excessive, or the lack of transportation was an insuperable barrier to fulfilling the bureaucratic steps to access the BPC. When we explained the scope of the benefit, disability caused discomfort, and women paraphrased us describing the benefit as the “child’s salary”.31 With very rare exceptions, we did not hear other ways of families referring to the benefit than as “salary”. “Disability” was never assumed as an emic category to describe the “special child.”

most families did not receive the cash benefit transfer for disabled children

The paraphrase of the “social assistance for children with disabilities” to “salary for the special child” accommodates family sentiments, but, from a rights perspective, it can also present a challenge for reviewing the strict criteria for receiving the social assistance. More than half of the women engaged in paid work before their pregnancy (53%, n = 26); of these, less than one fourth had returned to work (n = 6). Most

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30 According to information from the Ministry of Social and Agrarian Development, obtained through LAI, in March 2017, there were only 96 active BPC benefits for children diagnosed with microcephaly in Alagoas. The Ministry was not able to provide information, however, on how many were designated for children with congenital Zika syndrome.

31 The benefit is distributed to poor families who have a member with disabilities. So, the disabled person is the one entitled to be protected by the social assistance and not the caregiver.
of them worked in domestic jobs, in agriculture, in commerce, or in education. The impact on working life was equally felt by all women: education was not a decisive indicator as only one of the women with higher education had returned to work. To different degrees, all of the families had experienced losses compared to their previous standard of living given the considerable increase of expenses with transportation or health care,\textsuperscript{32} in addition to the concentration of the women’s time on domestic tasks and childcare.

The BPC is decisive to the survival of the family and the guarantee of care for the child, but its metaphor as a “salary for the special child” has consequences for the wellbeing of the family and their access to other fundamental rights. The most important of these is that, by requiring an extremely low level of income for families to access the benefit, there is no incentive for women to return to paid work. In addition, in the families with one child (55%, n = 27) or two children (20%, n = 10), we heard calculations regarding the father’s exit from the formal labor market so as not to disqualify the family on the basis of income. This is a common discussion among women in the digital communities, but difficult to apprehend in the context of the interviews, in which the families circumvented questions about family income due to legitimate fears about the misuse of the information.

The woman’s exit from paid work has immediate negative effects for the family income, but also for various domains of her life: the woman becomes a full-time caregiver, becoming responsible for ensuring not only the wellbeing of the child, but also for the family income, the “salary for the special child”. On the one hand, the income is conditioned on the woman remaining at home as the caretaker, but the income itself is not hers in title. This slippage from “benefit for disability and family poverty” under the terms of the law to “salary for the special child” in familiar terms has several meanings among rural communities, where the BPC for labor assistance is described as the “retirement” benefit.

“One day I took the bus. A woman looked at me and asked, Is he a mosquito-baby, yes? That hurt me a lot.”
For the context of the women caregivers, this sliding should not be underestimated in terms of the guarantee of rights: the daily lives of the women becomes that of caregivers, but the social assistance is for the child, and not for his/her relation of dependency on the mother. There is a disappearance of the woman caregiver with rights or needs, and the emergence of a figure of extreme maternity – be it for the care of the child or for the survival of the family. As a caretaker, the woman as a citizen is non-existent for social policies related to income transfer or retirement contributions. Even if she returns to paid work, her years of care will have lasting exclusionary effects, especially for those with low schooling.

Several families did not receive the Bolsa Família benefit.33 Bolsa Família is universally recognized among families, but two justifications were presented for the low adhesion: first that the Reference Centers for Assistance (CRAS) inform families that the two benefits (BPC and Bolsa Família) were not allowed for the same child; and second that the women would not risk losing the BPC, which provides a higher amount of money than Bolsa Família, by trying to obtain a second benefit.34 There is a political reform movement in Brazil toward the restriction of social benefits – whether by misinformation or negligence, several families reported resistance from CRAS to authorize the request for the two benefits for the same child. It is important to note that there is no normative restriction on the two benefits for the same child.

Of the 25 adolescents who became pregnant during adolescence with a child confirmed or under investigation for Zika, 40% (n = 10) were not participating in any income transfer programs, that is, they were not recipients of BPC nor Bolsa Família. When we analyze the two benefits separately, the exclusion is even more severe – 76% (n = 19) did not receive BPC and 44% (n = 11) did not receive Bolsa Família.

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33 Bolsa Família is an income transfer program for very poor families, stratified into two groups: the extremely poor, those with a monthly income of up to US$25.00 per person; the poor, with monthly income between US$26.00 and US$50.00 per person. The monthly amount of the transfer depends on the number of children in the family, but it is around US$30.00 per child between 0 and 17 years. The maximum amount to be received per family is US$100.00. It is estimated that more than 13 million families in the country receive the benefit. The Bolsa Família Program was created by Law no. 10.836, dated January 9, 2004.

34 We do not know who is the person at CRAS who provides this information. When we asked the women, they were not able to identify the position of the professional.
of the 25 adolescents who became pregnant during adolescence with the child confirmed or under investigation for Zika, 40% were not participating in any income transfer programs

According to the women, the orientation of various CRAS is that women under 18 years of age could not be direct beneficiaries of the benefits, only as dependents of adults. It is at the intersection between different policies that the precariousness of the lives of adolescent mothers becomes more acute: out of school, they are not eligible for Bolsa Família in their family of origin as daughters because the criterion of inclusion for the program is enrollment in school; as single and full-time caregivers they do not fulfill the required 75% school attendance for adolescents between 16 and 17 years of age; teenage mothers without any record of civil emancipation are not understood as subjects of rights for the assistance benefits for their children with congenital Zika syndrome. The alternative for some adolescents was to register the child as a dependent of the grandparents, despite living in different residences.

The child with congenital Zika syndrome demands intensive and daily care: the most important of these is the daily observation of signs still unknown by medical science. The science of domestic care anticipates clinical observation, and exchange among the women in the digital communities is intense. To ignore the importance of women for children with chronic diseases or disabilities is one of the injustices in Brazilian society. However, given the scenario of the epidemic, there is a second aggravating factor – science needs women caregivers as the primary observers of the signs of congenital Zika syndrome. It is time consuming, but it also transforms the meaning of this caregiving time beyond the domestic and family spheres to part of the response to the epidemic.
Transportation and health

Travel to health centers for early stimulation was one of the most explored topics in the interviews: the distances, even for a small state like Alagoas, considering the dimensions of neighboring Pernambuco or Bahia, are excessive. In most of the municipalities visited, there is no public transportation to the state’s two reference centers for the early stimulation of children, in Arapiraca and in Maceió. Over half of the women (55%, n = 27) depended entirely on the transportation offered by the city government – ambulances or chartered cars – to take their children to weekly 30-minute early stimulation sessions. The remaining women reported not having transportation from the city government, which means that 45% (n = 22) of the children do not receive assistance...
with early stimulation. Given the distances between the municipalities and the closest reference centers for early stimulation, the average time of travel was 3 hours for each woman and child (the ones with the shortest trip duration were those who lived in Maceió or Arapiraca; the more distant ones traveled up to 6 hours for a 30-minute early stimulation session or medical consultation).

**45% of children do not receive assistance with early stimulation**
There were abundant transportation stories involving risks and mistreatment. The collective vehicle is an ambulance that collects and transports all patients from the same community, no matter their conditions of dependency or illness. For 30 minutes of early stimulation once a week, the children leave the house at dawn and return at night as the ambulance fulfills its route and collective agenda: it collects everyone, then waits for everyone. There is no compliance with safety standards and very different individuals seeking out care share the same space in the windowless back of the ambulance.

One of the characteristics of the congenital Zika syndrome is the manifestation of irritability, spasms, or seizures in children. Some have eating peculiarities due to swallowing difficulties. Others require prostheses or orthoses, the most common of which are glasses. None of the mothers interviewed had received eyeglasses via the public health system and although 47% (n = 23) of the children used medication continuously, only 26% of them (n = 6) received the medications via the public health network. About one in two families (56%, n = 13) who needed to buy medications to control seizures or irritability reported not having the conditions to buy the medications without assistance.

35 A common event during the interviews was the child having seizures and spasms. This was an opportunity for the mothers to show us what they described as frights. In the virtual communities, there is a constant exchange of videos of these episodes with the children and the mothers switching between the medical language of convulsions, with the greatest fear that it be described as “epilepsy”, and the familiar “fright”.
The urgency of rights
Maria José Santos de Araújo is known as Neguinha and she is the mother of three children. Her youngest daughter was affected by Zika during the pregnancy. Neguinha lives in Japaratinga, a tourist town in Alagoas, in a house shared with her grandfather, a silent man during the conversations. Neguinha’s husband spends periods of time away from home. He works in the cane fields during grinding season; he has work three months out of the year. Melissa Vitoria was born in April 2016; she is part of the second wave of children affected by Zika in Alagoas. Neguinha’s first child lives with her grandmother in the distant backlands of the state, a story common to teenagers in Brazil who became pregnant at a very young age. Neguinha had her first child at age 16 and is now 20.

Neguinha felt the symptoms of Zika infection in the second month of pregnancy but notes the disease still has not left her body – her joints hurt and her legs feel heavier than before. The same month that she had Zika, she confirmed she was pregnant using a pharmacy-bought pregnancy test, but the public health clinic asked her to wait until the fourth month of pregnancy to start prenatal care. Throughout her whole pregnancy she had only one ultrasound, the same one in which she learned she was pregnant with a girl. She only found out about the microcephaly at the time of delivery, a moment that Neguinha recalls with her eyes engulfed by tears.

“When I had her, the midwife grabbed her and said – ‘She has microcephaly, right?’ And I said ‘What?’ She said ‘Microcephaly, did you know?’ and I said no. She said, ‘Look, here, look, and then she held her upside down.’ After this exchange, Neguinha says that she closed her eyes; it was her husband who accompanied their daughter to another room. The midwife returned to talk with Neguinha, a memory that still bothers her, describing

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36 Maria Jose asked to be presented as Neguinha, her nickname
it as “the greatest offense” – “She asked, ‘Are you going to take her home or are you going to leave her here?’ Neguinha and her husband were offended and the hospital apologized for the mistreatment.

This was not the only experience of discrimination that Neguinha suffered, and unlike other women, the language of rights and prejudice is salient in her narrative. Early on, her daughter became the subject of curiosity in the neighborhood, and Neguinha learned she was described as a “toad”. She and her husband thought of “taking it to court” because “this is prejudice”. But there were no legal proceedings, the neighbors advised them to trust in god.

Neguinha did not abandon her daughter; she takes care of her and her two-year-old son. At the time of the interview, in December 2016, she had not been receiving any cash benefit transfer. Due to her civil union with her husband it was required that both their documents be filed with the disability doctor and with social security services. However, the mill retains her husband’s papers until the end of the grinding season. Meanwhile Neguinha survives as best she could. The report from Melissa Vitória’s head CT states “microcephaly with neuropsychomotor repercussions. Calcifications in both hemispheres”, a very common description of the effects of Zika.

There are no early stimulation services in Japaratinga, the reference center is in Maceió, 130 km (80 miles) away. For a half-hour session each week, Neguinha has to go to the Health Department the day before with her daughter to schedule the transportation and be ready for pickup at the health clinic at 4:00 a.m. She has to travel the distance from her home to the clinic by foot and it takes half an hour. After several trips in vain because the car filled up before her daughter’s consultation was given any priority, Neguinha gave up taking her daughter to appointments. Limited to travel via ambulance and without the right to bring anyone to help her, Neguinha does not leave Japaratinga – she cannot travel to the capital for consultations with the two children, Melissa Vitória in her lap and her two-year-old brother.

37 After initial denial and subsequent appeal Neguinha started to receive the BPC. Eleven months went by between Melissa Vitoria’s birth and the first payment.
The house has two rooms, and in the same room in which you enter, you also cook and sleep. In the room in the back, there is a bathroom and another bed. There is a single window. The bathroom is in the back of the house. The bright blue walls give light to the crowded interior packed with children: Patrícia Santos da Silva has six children. She is 24 years old, and had her first child at 14. To get to the tiny house, it is necessary to go around the church of Santana de Ipanema, the great city of the Alagoas backlands. The kids followed the conversation in silence, the one in her lap is “patient zero” of Alagoas. Patient zero is a name given by medicine to the first case identified in a given region – Gabriel is unaware of how his life was affected by what his mother describes as the “tiny mosquito problem.”

Patricia did not attend school regularly and she lives as she can with the income from her husband’s temporary jobs. Her son was not receiving the BPC, there were missing documents from her and her husband. They were essentially a family with no documents, so a volunteer lawyer had offered to help them navigate the bureaucracy. The household survived on the benefits from “Bolsa Família” – the rent was around U$190.00 and their needs did not have to be listed, they were evident all around them.

Patricia listed the “pharmacy of medications” for her son Gabriel but explained that she did not receive or buy any medication. She showed us the prescriptions – antiepileptic medication was the first one on the list. She complained that her son did not sleep, but she did not have the means to get to the doctor and only occasionally attended the early stimulation sessions offered by a philanthropic group in the city. She had
heard that the boy would need glasses, but is going to wait for him to start school to take care of it.

She only found out about the “tiny mosquito problem” at the delivery. Patricia had a single ultrasound, the same one that confirmed her pregnancy. She does not recall the exact date, but it was after developing a rash and body aches. She had Zika without even knowing she was pregnant. She does not know the dates of the pregnancy, nor the exact ages of her children. In the delivery room, the nurse told her that the “boy with the small head was special.” It was then that it was explained that he had been born “with the tiny mosquito problem.” On the same day that Gabriel was born, another child in Santana do Ipanema was also reported and confirmed as having congenital Zika syndrome, but his mother does not believe in the diagnosis38.

Like Neguinha, Patricia was also asked in the delivery room if she would abandon the child, and she was surprised because she was already the mother of five: “The nurse asked me if I would leave him at the hospital. I said no, then she told me to give him lots of love and affection.” The advice was not understood in any other way by Patricia; on the contrary, she explained that the nurse emphasized the importance of affection because Gabriel is a “special child.” From all the families, we heard “special” not as a euphemism for the medical diagnoses, but as a statement of the child’s place among the family and community.

Patricia did not hesitate to announce to all her other children that Gabriel was the most beloved exactly because he was a special son. The sense of comfort and inclusion are salient in the affectionate use of the word “special.” She shares that when she goes out with Gabriel, the neighbors ask to take his hat off so that they can see up close the “mosquito child they only see on television.” She explained to us that people do this because Gabriel is “a special child” and everyone likes him.

38 The child has microcephaly, hip dysplasia, vision impairment, and cardiac problems. The mother had a rash for one day during her pregnancy. Patricia told us that she did a blood test to confirm whether it was due to Zika and the result was negative. There is no record of this in the public health registries and it is also unclear what would have been this “test” she took. At the time of her delivery, there was no test available in the public health system for Zika virus.
Robéria Cabral de Lima,

the orphan son

São José da Tapera is a town in the Alagoas backlands. We had nine cases in the city: one confirmed, five discarded, and three under investigation. Our starting point for one of the discarded cases was the registry of a mother’s death shortly after delivery. We went out looking for Robéria’s home at the local moto-taxi stand. The girl was not well known – we tried what we had utilized in the communities already visited, “we are looking for a child with a tiny head”, “a child with the mosquito problem.” The guide picked up on the word “head” and took us to a distant location, “Sítio Água Salgada” (Salt Water Farm), where water only arrives by water trucks. There was no vegetation around, only tiny houses far from each other. Cell phone signal was rare.

The first house we stopped at had barely any furniture, there were many women, and a few children. It was a household known in the community as the family “with the altered nervous system, with head problems”. It was not Robéria’s house, but the motorcycle taxi driver did not give up, he followed clues to what we described as pieces to a puzzle – he had heard the case of a mother who had died months after giving birth. The child lived with the grandparents. We went to the house of Ms. Bita, Robéria’s mother and João Henrique’s grandmother.
João Henrique was born in January, Robéria died in March of 2016. She never left the hospital after giving birth; he left with a report indicating ICD “Q02”: in medical language, a code for “microcephaly”. Ms. Bita is a talkative woman, she just did not know how to explain what her daughter had died from or the reasons her grandson had tremors or was easily startled. “His head is banged up”, she explained. Her daughter’s and grandchild’s medical folder was impeccable: everything was documented – Robéria had died of respiratory failure. “Her blood thinned,” she explained, as we read the death certificate and looked at the pictures of her dead daughter hanging in the living room.

Robéria did not get to care for her son at all. The boy cried with hunger and it was Ms. Bita’s sister, who was also breastfeeding, who shared her milk with the boy. On March 8, Robéria got dressed up in the hospital: it was the International Women’s Day celebration – she fixed her hair and received flowers, says Ms. Bita. But her daughter felt different, “Mother, I think I’m going to die.” Nobody in the household remembers if Robéria had Zika during pregnancy, only the usual viral illnesses, they explained. They survive on what they grow in the fields, but the land is not their own, they are sharecroppers.

Since then, the family has been waiting to gain access to cash benefit transfers for the baby. In December 2016, the family had been seeking out doctors and experts for 9 months in search of the required paperwork for the benefit. The report with the ICD Q02 diagnosis was dismissed by the INSS (the Brazilian Social Security services) expert who said the child was “normal”. Ms. Bita finds this strange, because the boy does not sleep. Robéria’s exams for TORCH infections were negative and Joao Henrique only had one CT scan which found “other alterations.” We left the house of the orphaned son and went to the house next door which had a confirmed case, the mother was just arriving from the capital after a day of examinations and was balancing her child between her body and the motorcycle driver. The ambulance had left her on the highway and from there her only options for getting home were bicycle, on foot, or on a motorcycle.
Rakely Santos da Silva, 

the teenager mother

We met Rakely with her 8-month old daughter, Mirela Santos de Oliveira, and the baby’s grandmother, Ms. Rosângela, chatting outside their home in the village of Santa Luzia. The community was once a settlement of the Landless Movement (Movimento Sem Terra); today it is piece of land on the north coast of Alagoas and surrounded by a coconut grove between two famous beaches, Paripueira and Barra de Santo Antônio. Rakely has a childish smile. She is a teenage mother, who married at 14 and gave birth at 15. At first glance, it seems that the two girls are the daughters of Ms. Rosângela, a young grandmother herself.

Rakely does not work; her husband gets temporary jobs here and there. When he gets a job, he makes up to U$21 a day. But it is not a steady thing. In the family, the only sure money is from the “Bolsa Família” benefits in the name of Ms. Rosângela – Rakely was not entitled to be a beneficiary because she is a teenager. They tried to also get BPC but were denied: mother and daughter reported that a lawyer knocked at their door proposing a business deal commonly offered to other women we interviewed – to fight in court in exchange for the eight months of the unpaid benefit as payment for his fees.
Mirela was born with a 31 cm head circumference and was reported as a possible case of congenital Zika syndrome while still in the maternity ward. Before we even asked, Rakely described the symptoms of itching and redness in pregnancy as “I had Zika.” She went to the health post and the doctor gave her an injection. Mother and daughter are unaware of the name of the medicine given to take care of the effects of Zika. At two months, in compliance with the health protocol for Zika in Alagoas, Mirela had a computerized tomography, the report which announced her case to be discarded, with the following diagnosis: “CT performed – altered results, with other alterations.” In the space for results it read: “not informed”.

Grandmother and mother only think of opening Mirela’s “little shut eye”. They do not care about the cash benefits or medications to calm the child, what they want the most is an ophthalmologist to open her eye that was born glued. The medical report describes the “glued eye” in a more dramatic manner: on the paper it is written as “ocular absence”. As we read the report aloud, we asked the two women if they understood what was written or if someone had already explained it to them. The answer was “no, they never explained anything to us, we just got a phone call from the social worker.”

In the interview, Rakely said she used an injection to not have more children. The response was not very convincing, but there is no way in the first meeting to dwell on sensitive topics. The mother did not leave her daughter’s side during the conversation. Rakely and Ms. Rosângela took down our cell phone numbers and WhatsApp became a form of communication. A few days after the interview, Ms. Rosângela contacted us. The call was quick and the explanation direct: “It is not time for more children, the community health clinic does not have the injection and taking pills every day is not reliable for those who care for small children. Can you get an injection for Rakely?”
João Lucas is the first child of Tamires and Eduardo Goldino Filho, the child was planned, and is the second grandson of Ms. Maria Lucia. The interview happened in the late evening. Tamires is a teacher and we had to wait for her return from the neighboring city, Jacaré dos Homens, where she is a school monitor. Ms. Maria Lúcia lives in Lagoa de Araras, Tamires and Eduardo live in Agreste. The two cities have Santana do Ipanema as the metropolis of the backlands.

Tamires studied a lot and was working on her second bachelor’s degree when she became pregnant with João Lucas. She had Zika around the fourth month of pregnancy, and on the third ultrasound she discovered what the grandmother describes as the child’s “tiny problem”. Ms. Maria Lucia doubts if everything João Lucas has really came from Zika, because how is it that a mosquito, “a little something like that would cause such a big problem?” At the same time, she is resigned to what the doctors say – “It was Zika”. 
João Lucas cried a lot in his first months of life; Ms. Maria Lucia remembers her grandson’s intense fussiness, and reinforces how tender her daughter is when caring for him. With each description of the medications or frights, she would add “she takes such good care of him, imagine, she has such patience with him, she dresses him all up to go to mass.” She kept telling us how much her daughter cries during mass on Sundays as she prays. She settled on her words, saying that “João Lucas was sent by God”, also the title of a social media page in which the family shares the daily life of the child.

Tamires arrived by motorcycle with her husband. Her big smile showed the mother’s described tenderness; by her side, as if an extension of her own body, was her husband, a serene man. Indignation was the tone when they talked about the difficulties they had traveling with João Lucas to early stimulation in Arapiraca. They consider the ambulance an offense and a life hazard. Eduardo showed us the footage made in the back of the ambulance: he is carrying the child on his lap as if his body were a protective shield. The trip takes almost two hours each way.

The ambulance ride is an outrageous mode of transportation for several reasons. The first one is the terrible physical arrangements – the back of the ambulance has benches along the sides, a tiny window that is more of a vent that circulates little air, and no seat belts or child car seats. The second reason is that people are transported as a group: João Lucas has low immunity, Tamires explained to us, but he is not a sick child. There are people of all ages and needs in the same space, and the ambulance works as a local train: picking up and dropping off people, there is no such thing as a scheduled time for an appointment. It leaves as early as possible and it returns as late as necessary. João Lucas does not like the trip: physiotherapy day is once a week, but it is also a journey of hunger, fatigue, and insomnia.

39 In May 2017, Tamires informed us that the transport is currently available and in good conditions.
The end of the epidemic
The Brazilian Ministry of Health announced the end of the emergency situation for the Zika virus epidemic on May 11, 2017. Each year the numbers of children born with microcephaly and subsequently diagnosed with congenital Zika syndrome have been decreasing. Since the beginning of the epidemic, there have been 2,653 confirmed cases and 105 cases of probable congenital Zika syndrome in the country. In 2017, Alagoas registered 3 confirmed cases; Bahia, 40; Paraíba, 0; and Pernambuco, 4. The women at risk of the third wave of the mosquito season are now pregnant and we will know the effects of the “end of Zika” by the summer months of 2018. They will be mothers of children affected after the end of the epidemic in Brazil.

This report challenges the meaning of “end of Zika” or the Brazilian government’s “good news”. The data presented here should not be interpreted as the portrait of a particular tragedy, that is, as the disastrous manifestation of the state with the country’s worst HDI. If there is no paradox between Alagoas and its neighboring states, there is also no paradox in terms of the abandonment of women and children as occurs in the rest of the country. The situation in Alagoas is a piece of the mosaic of the abandonment of the women living in Zika-affected lands. They are teenagers or very young women, Black, Brown, and Indigenous women, with little schooling and out of work.

The families with children affected by Zika were informed of the “end of the epidemic” via the national news. Some of them take care of their children without knowing exactly what causes them to have seizures or keeps them from walking. The cases of children that were discarded for congenital Zika syndrome by the criteria established at the onset of the epidemic have not been re-evaluated by the health system. According to the Ministry of Health’s Epidemiological Bulletin number 48/2017, for each case confirmed or classified as probable, one remains under investigation for congenital Zika syndrome, and around three have

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41 On May 11, 2017, the Ministry of health declared the end of the emergency public health situation. There were news reports describing this as “good news.”
been discarded or excluded.\textsuperscript{42} There is a slowness to getting the correct diagnosis, with dramatic effects for the care of these children.

Alagoas is one of the states at the epidemic’s epicenter that has the most discarded cases. When compared to Bahia, Alagoas discarded almost twice as many cases.\textsuperscript{43} The low incidence of children with congenital Zika syndrome was described as a paradox between Alagoas and the giants of the epidemic, Bahia, Paraíba, and Pernambuco. Our thesis is that there is no paradox, but that the numbers emerged from the particular design of the state health policy that perhaps led to the precipitated discarding of cases. In an epidemic, different professionals should be trained to implement rapid diagnosis. Our insistence on the incongruity of having the radiologist’s report be the gateway for diagnosis is because of the peripheral position that this specialty has in national awareness and training policies for diagnosis at federal and state levels. A new epidemic causes destabilization in the ways of identifying and diagnosing an illness; it requires putting together small pieces of a puzzle for which the full picture is unknown.

Here we are, the day after the end of the epidemic in Brazil. The numbers and stories presented here demonstrate the face of inequality in Brazil prior to the arrival of Zika. It was the most vulnerable women who were the most affected by the epidemic – they and their children now live a situation considered to be resolved by health policies. If there was an urgent need to ensure rights under the national emergency declaration for the Zika epidemic, there is now an urgency in relation to the effects of a humanitarian tragedy that may easily be forgotten.

The women and their families cannot be forgotten. They are survivors of an epidemic that could have been avoided if the vector were not abundant in the country, if sanitation and public health conditions did not force them to hoard water or survive on the periodic water distribution by water


trucks. The vast majority of women experienced their first pregnancy as teenagers. They are young women out of school and out of the workforce with their lives now marked by the story of the Zika epidemic in Brazil. Unsurprisingly, they are also families that have been neglected by social assistance policies.

The great epidemics have already been described as “poverty traps”.44 The term is provocative, as it describes the survival of the families in Alagoas and other affected Brazilian states: they were women already made vulnerable by social inequality and by historical regimes of racial and regional exploitation. These are women surviving through the sale of crabs, through the “Bolsa Família” cash transfer program, or through working on someone else’s land as a sharecropper.45 None of them are at the top of Brazil’s social class stratification. The Zika epidemic has plagued families already living fragile circumstances because of inequality, and the perversity of the declaration of the “end of the epidemic” is that it can lead to forgetfulness as if Zika were a disease of the past.

For these women, the classic idea that an epidemic would have a beginning, a peak, and an end is a fable.46 The Zika epidemic will never end for the mothers of children with congenital Zika syndrome: their motherhood will be intense, full of love but also solitary. The abandonment they experience is not the result of the birth of a child with special needs, but of the fragility of social policies, particularly those related to social assistance, health, and transportation. In October 2016, the Ministry of Social Development announced the Happy Child Program to prioritize

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44 “A poverty trap is defined as any self-reinforcing mechanism that causes poverty to persist. Poverty traps do not refer to situations in which it is simply difficult to escape low incomes but to a situation where the evolution of household wealth or well-being is governed by a path-dependent process such that, depending on initial conditions, otherwise identical individuals or households may remain for long periods of time (if not indefinitely) “locked into” poverty or affluence. A key characteristic of a poverty trap is that “good” and “bad” outcomes are self-enforcing, so that small interventions or chance events will not alter the long-term outcome.” MASANJALA, Winford H. HIV/AIDS, Household Income, and Consumption Dynamics in Malawi. Em: Gillespie, Stuart (Org.). AIDS, Poverty, and Hunger: Challenges and Responses. Highlights of the International Conference on HIV/ AIDS and Food and Nutrition Security, Durban, South Africa, 14-16, 2005. Washington, D.C.: International Food Policy Research Institute, 2006, p. 58.

45 These were just some of the occupations of the women we interviewed.

social protection for pregnant women and children up to 6 years.\textsuperscript{47} in Alagoas, more than half of the families did not receive the cash benefit transfer for disabled children; one in every two children who needed medicines did not receive them for free; almost half of the children who were already of age for early stimulation were not included in specialized programs.\textsuperscript{48}

The women from Zika-affected lands do not expect a guarantee of happiness from social assistance, only the support and conditions for a dignified life. The fable of the end to an epidemic is not a reality for women who transport their children in the back of an ambulance or clinging to their bodies on the back of a motorcycle taxi. The mosquito has not disappeared from the Brazilian backlands, science has not yet provided a definitive answer to the risks of sexual transmission of the Zika virus, or the delayed manifestation of signs of the congenital syndrome in children. These uncertainties are sources of distress and suffering for women of reproductive age. Zika is still an epidemic.


Recommendations
At the State and Municipal levels

To the Health Secretariat for the State of Alagoas:

➢ To the Superintendence for Health Surveillance:

Diagnosis of Zika virus infection

• Train health professionals to clinically diagnose Zika virus infection, especially in pregnant women;

• Offer pregnant women prevention care for TORCH-Zika infections at the first prenatal visit. Any pregnant woman who reports a rash or any other symptoms of TORCH-Zika infections should be referred to an infectious disease specialist for evaluation;

• Collect blood, urine, and cerebrospinal fluid samples from pregnant women in TORCH-Zika cases as soon as possible, and keep them fractionated and properly stored for subsequent analysis, as recommended by the Ministry of Health.

Diagnosis of congenital Zika syndrome

• Guarantee the provision of a second ultrasound to all pregnant women in order to allow the early diagnosis of fetal congenital Zika syndrome. The report for the second ultrasound should be standardized to ensure that all relevant aspects for the identification of congenital infections are evaluated;

• Train all professionals who work in the delivery room on the proper measuring of head circumference (HC), interpretation of the anthropometry tables, evaluation of the gestational age of the newborn, and notification of other alterations suggestive of congenital infections. Special attention to avoid the discarding of cases of congenital syndrome with no signs of microcephaly should be prioritized;
Delegate to a pediatric infectious disease specialist or someone experienced in congenital infections the imaging criteria and serology tests to confirm the diagnosis of the congenital syndrome in newborns starting at their first pediatric visit. Computerized tomography (CT) should not be adopted as a standard procedure (high level radiation; costly to the health care system; requires sedation to the newborn).

Reassessment of discarded cases

- Refer for medical reassessment all reported cases that were discarded for congenital Zika syndrome in Alagoas (and in all Northeastern states) to recheck the diagnosis according to the current criteria adopted by the Ministry of Health;
- Refer the discarded cases to social assistance in order to confirm whether there are other pregnant women or babies born at the same time in the same household who might not have been evaluated or reported to health surveillance.

To the Superintendence for Health Care:

Provision of health care for children affected by the congenital Zika syndrome

- Schedule the first visit of each newborn to a pediatric or other professional with infectious disease specialization within 15 days after leaving the maternity ward. The delay in reaching a specialist might cause risk of irreversible damage and even death;
- Guarantee access to early stimulation (auditory, physical, intellectual, visual, in ostomy and in multiple disabilities) for all children affected by Zika syndrome, at least three times a week, and within a distance of up to 50 km from the family residence;
• For families who reside more than 50 km away from the nearest health care facility for early stimulation, guarantee free transportation for treatment in appropriate, safe, and regularly available vehicles for the child and his/her guardian;

• Offer training courses for professionals on the provision of specialized, multidisciplinary, and comprehensive care for women, families, and children affected by the Zika virus epidemic;

• Produce educational material, with an emphasis on digital information for social media and accessible language, about early stimulation, daily infant care, and policy rights.

Support for children with congenital Zika syndrome

• Provide a comprehensive medical report describing all symptoms suggestive of congenital infection for all children reported as having congenital Zika syndrome to access the social assistance benefits without the need for an additional medical report by a second health care team (mainly BPC);

• Ensure that children affected by congenital Zika syndrome who are dependent on intensive care are eligible for home care and the full package of health supplies and social supports for in-home care.

Medications, Equipment, and Supplies

• Ensure the regular and free distribution of medications to control the symptoms of congenital Zika syndrome, such as anticonvulsants (phenobarbital, carbamazepine and others), mood stabilizers (pericyzine and others), food supplements, and vitamins;

• Ensure the free supply of diapers for children affected by congenital Zika syndrome through the Brazilian People’s Pharmacy Program, especially for those who still need to use them after the normal age of potty training;
• Ensure free access to glasses, orthoses, prostheses and other equipment necessary for the development of children affected by congenital Zika syndrome.

**Family planning and reproductive health**

• Ensure free access for all women of reproductive age to all contraceptive methods, and include access to long acting reversible contraceptives, such as levonorgestrel hormone-releasing IUD (IUD-LNG) and hormonal subdermal implant among the methods available in the public health system;

• Ensure free access for men and women to methods for prevention of sexually transmitted infections;

• Ensure free access of mosquito repellent for all pregnant women and their male partners;

• Carry out a campaign to promote access to information on modes of transmission of the Zika virus, covering all dimensions of forms of transmission and protection.

**Mental health**

• Train multidisciplinary teams to provide psychosocial care for women affected by the Zika virus epidemic;

• Provide multidisciplinary mental health services to pregnant women with Zika;

• Provide multidisciplinary mental health services as part of post-abortion care for women with Zika;

• Provide multidisciplinary mental health services for women in the delivery room after diagnosis of microcephaly in the newborn;
• Provide multidisciplinary mental health services for women whose children died due to congenital Zika syndrome;

• Provide multidisciplinary mental health services for families whose children were born with congenital Zika syndrome.

To the Social Assistance and Development Secretariat for the State of Alagoas

• Promote training modules (face-to-face or distance learning) for the professionals in charge of direct social assistance activities on demands related to the Zika epidemic. The training should be carried out in partnership with public state universities, social oversight entities like the State Committee on Social Assistance, and community and non-profit groups;

• Produce educational material on fundamental rights and policies to be distributed among professionals and families;

• Ensure that the state social assistance governance will oversee family access to the social policies;

• Ensure training for social work professionals to actively reach out to children affected by the syndrome, including those erroneously discarded by the surveillance system.

To the Women and Human Rights Secretariat for the State of Alagoas:

• Work in coalition with other Secretariats of Alagoas to produce and disseminate information related to prevention, protection, and care for families and women caregivers of children affected by the Zika syndrome;
Promote educational and policy activities to ensure that women’s and girl’s rights and needs are at the center of public actions;

Ensure policies to address discrimination based on disability and to guarantee inclusion of Zika-affected children in social spaces.

To the Education Secretariat for the State of Alagoas:

- Include comprehensive sex education for adolescents in the state school curriculum;
- Review educational curricula to ensure information on women’s social roles in child care, work, and health;
- Create public daycare centers in Zika-affected municipalities and increase the number of spots in available centers, with caregivers trained to care for children with congenital Zika syndrome;
- Ensure that adolescent mothers are able to return to school, including the preferential placement of their children in public daycare centers;
- Ensure the inclusion of children affected by the Zika virus syndrome in the regular school system.

To public institutions of higher education in the State of Alagoas:

- Review and include updated information about the Zika virus epidemic and its social impact in curricula, especially in social service, law, and health care courses;
- Design specialization courses, lato sensu postgraduate, and/or master’s degrees courses for professionals dedicated to the care of children, women, and families affected by the Zika epidemic;
• Encourage research in a wide range of topics with community engagement throughout the whole research process;
• Create specific funding for multidisciplinary research on the impact of the Zika epidemic.

To the Territorial Development and the Environment Secretariat for the State of Alagoas

• Ensure that families residing more than 50km away from referral services for children’s care are entitled to affordable housing via existing social benefits;
• Ensure that families living in public housing receive the additional benefits of payment of water and electricity bills to guarantee family subsistence.

To the Transportation and Traffic Superintendence for the Municipality of Maceió

• Extend the application of municipal law nº 6.370/2015, which ensures the right to free public transportation for people with disabilities to all the children affected by the congenital Zika syndrome and their caregivers;
• Guarantee and oversee the conditions of free transportation for children to attend health services to ensure compliance with minimum rules of traffic safety.
Federal Level

To the National Institute of Social Security:

- Eliminate the 3-year cap for payments of the “Continuous Cash Benefit” (BPC) for children affected by congenital Zika syndrome, without a second medical reexamination by the INSS;
- Ensure the cumulative payment of the BPC with the maternity-leave payment for eligible mothers of children affected by Zika syndrome;
- Guarantee the maternity-leave wages of 180 days in the case of eligible mothers of children affected by congenital Zika syndrome.

To the Ministry of Social and Rural Development:

- Expand access for pregnant women in situations of social vulnerability to the “Bolsa Família” program (cash benefit program), accepting confirmation of pregnancy as sufficient for eligibility and no restrictions based on the age of the mother;
- Ensure that staff throughout the country receive training on how to assist and inform the families affected by Zika virus of available social assistance policies;
- Ensure that all families receive the benefits they are entitled to, offering clear information regarding the legal provision for multiple benefits in the same family.
To the Ministry of Health:

- Ensure the distribution of PCR and serological tests (IGM and IGG) for the detection of Zika virus infection to SUS (Brazilian National Health System) public health clinics;
- Review the protocols on the Zika virus epidemic and the response to the congenital syndrome in accordance with the guidelines issued by the World Health Organization (WHO) and the Pan American Health Organization (PAHO);
- Work in coalition with other Ministries to ensure that public schools offer health education regarding the modes of prevention and care for women of reproductive age;
- Train health professionals nationwide to properly diagnose and offer care to children affected by Zika syndrome, with a special focus on distance learning;
- Update the public policy on family planning and distribution of contraceptives to include long-acting reversible contraceptives, such as levonorgestrel hormone-releasing IUDs (IUD-LNGs) and hormonal subdermal implant;
- Include the effects of the Zika epidemic on the agenda of the next National and State Health Conferences.
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