

Social Assistance responses to Zika virus epidemic in Brazil

Fieldwork Report

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1. Descriptive Summary of Research

The complex and unprecedented characteristics of the Zika epidemic in Brazil demanded national and local coordination, the intersection of public policies (e.g., health, social assistance, education) and the creation of norms, procedures and protocols to attend the affected families. The epidemic highlighted the difficult living conditions of many marginalised families and emphasised the complex and longstanding challenges involving public health, social development, infrastructure, access to water and sanitation, gender relations and reproductive rights. Besides, since its treatment requires costly treatment and daily care, it has increased vulnerabilities and social inequalities that affect the mothers and children infected by the virus.

Despite the reduction of infection cases in 2016, leading the Brazilian state and the WHO to lift the status of health emergency, the long-term and severe impacts of SCZ on poor women and children remained. The disease increased social risks and required a state response that went beyond health treatments, epidemiological surveillance and combat of the vector. This response, for instance, was delineated in a context of economic and political crisis and shaped by multiple actors, interests and narratives at the national, state and municipal level.

The research presented at this fieldwork report adds to the numerous meetings and virtual exchanges that occurred under the Newton Fund project *'Building collaboration for Action Ethnography on Care, Disability and Health Policy and Administration of Public Service for Women and Caretakers of Zika virus affected Children in Pernambuco, Brazil'*. In addition to the ongoing dialogue between researchers from IDS, University of Sussex, University of Pernambuco, Fiocruz and the University of Brasilia, this report describes the work of the IDS researcher Isabele Villwock Bachtold conducted in the Brazilian cities of Rio, Recife and Campina Grande in 2018. It contains the findings of her independent research as well as her efforts to strengthen the partnerships between Brazilian and British institutions.

The research aimed at understanding the processes, discourses and actors involved in developing and implementing social policies targeted at the population affected by the Zika virus. The qualitative research privileged an interdisciplinary understanding of policy processes and was built upon primary and secondary data gathered through document analysis and semi-structured interviews. The research was conducted at the national and subnational levels: Federal Government, state and municipality of Rio de Janeiro and the municipalities of Recife and Campina Grande.

The fieldwork occurred in two different moments: three weeks in June 2018, in the city of Rio de Janeiro and four weeks in Recife in October 2018, including a short trip to Campina Grande. 25 face-to-face semi-structured interviews were conducted with mid-level bureaucrats and frontline workers in their workplace, most of them from the social assistance sector. Virtual conversations were also held with policymakers and coordinators who were involved in the designing of a social assistance response at the national level. Besides, since most of the state

responses involved integrated actions, some interviews were made with health and education professionals as well.

Concerning document analysis, a review was made regarding the current legislation and official guidelines addressing issues related to the Zika epidemics. These documents were produced by a range of governmental and international actors, such as UNICEF, Ministry of Social Development, Ministry of Health, state and municipal bodies. The documents were selected through a purposeful sample, based on preliminary research carried on official websites, and through the indication by interviewees.

In addition, the researcher had conducted institutional meetings with Fiocruz, UFPE and UnB teams through face-to-face and virtual encounters since June 2018. There were also virtual conversations with policymakers in Brasilia from the Ministry of Health and the Ministry of Social Development.

2. Objectives and Results

2.1 Analyse the underlying narratives, concepts and agency roles in the build of a social assistance response to the virus-affected population

The findings of the fieldwork research conducted in Rio in June 2018 were presented in the researcher' master dissertation submitted to the fulfilment of the degree of Master of Arts in Development Studies, at the Institute of Development Studies/University of Sussex. The dissertation 'After Emergency: Social Protection Responses to Zika Virus in Brazil', awarded with distinction, presents the underlying narratives that have framed policy processes related to the Zika Congenital Syndrome both at the national and subnational level in a moment of political and economic crisis, the state of Rio de Janeiro being the case studied.

2.2 Understand the social assistance response to the epidemic in the national and local levels as well as the inter-relations between the municipal, state and federal governments.

This goal was reached through primary and secondary data gathered during the two fieldwork trips to Rio de Janeiro and Recife. Despite the literature review, a documental analysis, a range of 25 face-to-face interviews and several virtual encounters were conducted with policymakers, mid-level bureaucrats and frontline workers between June 2018 and January 2019. In addition, the researcher handled several formal and informal meetings with researchers from the partner institutions in order to discuss preliminary findings.

2.3 Identify integrated actions that had shaped a social protection response and the intersectionality of the social assistance, health and education sectors

As mentioned, interviews were conducted mostly with professionals from the social assistance sector, although not restricted to this area. In some cases, most of the social assistance policies were enabled in practice through the work of social assistants and practitioners located in health facilities (hospital and primary care units). Interviews were conducted in hospitals and reference centres for diagnostic and treatments, such as the Brain Institute and Fernandes Filgueira Institute in Rio and the Multiclínica Hospital in Recife.

Concerning the education sector, the researcher had also interviewed professionals from the municipal departments of education in Recife and Campina Grande, as well as the state secretariat and the state coordination for special needs education of Pernambuco.

2.4 Engagement with partners institutions (Fiocruz, UFPE and UnB) in order to identify complementary topics for research and possible collaboration for publications and future research

Meetings and informal conversations were held in Rio with Fiocruz researchers and in Recife in June 2018. In September 2018, an institutional encounter between UFPE, IDS and Fiocruz took place in Rio in order to discuss preliminary findings, research outputs and future collaborations. A joint article between UFPE and IDS concerning the reorganization of services and policies to assist the affected population is currently under discussion.

2.5 Map governmental actors and other stakeholders involved in the health and social protection response to the Zika epidemic in order to seek future policy engagement activities

Besides the interviews with local and state governmental actors, the researcher had engaged with policymakers in Brasilia and held explanatory conversations in order to identify possible partners and spaces for a seminar in March 2019 to present the results of the research.

3. Preliminary Research Findings and Topics

3.1 What are the main social protection responses to zika virus at the national level? How were they defined?

- The involvement of the assistance sector in the state response to the epidemic outbreak was driven by two main demands: (1) to encourage campaigns to the combat of the aedes through the Social Assistance network (in the social assistance centres, due to

their capillarity in the territory), (2) to develop or adapt its services to better assist the virus-affected population.

- Rapid Strategy of Action – Right after the outbreak of the epidemic, the Ministry of Health and the Ministry of Social Development launched a joint strategy of the SUS and SUAS. The Rapid Strategy of Action (EAR, its acronym in Portuguese) organised health and social assistance facilities to locate children with confirmed or suspected cases, refer them to adequate health treatments and fast-track their families' access to social programmes and benefits. The integration of operational procedures and routines were detailed in two joint guidelines for states and municipalities, that prescribed information flows and actions both to the combat of the vector and to the assistance of the children and pregnant women.
- The guidelines were defined in inter-ministerial meetings, called by the Ministry of Health, with no further involvement of the affected population or civil society movements. There were some minor interactions with representatives from the state and municipalities that were most affected.
- Budget – no extra budget was allocated to state and municipalities, despite a small amount of R\$2.4M (around 500,000 pounds) to co-finance day-care centres in eleven municipalities (Centro-Dia, see below).
- BPC (Continuous Cash Benefit) - the inclusion of the affected population in the BPC Programme was mentioned as the main social policy response to the epidemic. Established by the 1988 Constitution, the BPC provides unconditional, guaranteed monthly income equivalent with the minimum wage, to persons with disabilities or people above the age of 65 who can prove they have no means of supporting themselves. In what concerns the zika epidemic, some procedures were adapted to help the families with the administrative requirements (e.g., scheduling of appointments and the provision of the medical report at the diagnosis centre instead of at the pension units) and priority was given to children with microcephaly in accessing the benefit. However, no changes were made in the income eligibility criteria, and a three-year limit was imposed to the access of the benefit by this group, a requirement that was seen as a restriction on rights since it is not mandatory for other beneficiaries of the BPC.
- Active Search - Due to the capillarity of social assistance services in the territory and, also, to the recognition that most of the affected population were in a situation of vulnerability or living in poor areas, the social assistance network was involved in locating the pregnant women and children diagnosed with microcephaly. The EAR and ministerial guidelines established the communication flows and procedures to identify the affected population and refer them to the primary care units.
- Family care - The Social Assistance Unified System (SUAS) has services to assist families at social risk. The local Reference Centres for Social Assistance (CRAS) support vulnerable families through the provision of social and material assets and by promoting collective spaces of dialogue and exchange of family experiences. The Ministry of Social

Development provided recommendations and guidelines regarding the inclusion of virus affected population in those services.

- Centros-Dia - Centros-Dia are public facilities from the social assistance sector that assist people with disability and their families. At the beginning of 2018, the Ministry of Social Development announced the co-financing of 11 centres for children with microcephaly and other severe neurological diseases. The centres are intended to host for some hours per day the children and their caretakers while providing leisure, counselling and group activities. It was alleged by the Ministry of Social Development as an innovation and a response to the Zika epidemic. However, the municipalities had to co-finance the facility, while affording most of the daily expenses. Hence, the allocation of the centres was dependent on the ability/budget/political will of the municipality to host and afford them. There were not centres in Rio or Recife, two of the most affected cities.
- Inclusion in existing services and policies – the narrative presented by the Ministry of Social Development frames the social protection responses to the syndrome in terms of inclusion of the affected population in existing social policies, instead of creating or adapting new policies or actions. The eligibility criteria for social benefits were strictly maintained, while access was hampered by controlling and targeting measurements. The income criteria of BPC and other social benefits remained inflexible, not considering the increasing expenses of medicines and treatment.

3.2 What are the main social assistance responses to zika virus at the subnational level? How were they defined?

- Following the structure of Social Assistance Unified System (SUAS) and the guidelines established at the EAR, the social assistance services in Rio, Recife and Campina Grande were focused on the Active Search of the affected population, provision of access to social benefits and inclusion of the families in social assistance network. Due to the nature of the work in the subnational levels, there was a closer engagement of mid-level bureaucrats and frontline workers with the affected population (reality-check). These agents act as ‘brokers’ to ease the access of the affected population to rights and social benefits.
- At the frontline level, social workers from the health and social assistance units have established personal networks to instruct the families better and ease their access to social benefits. Some actions go beyond their assigned responsibilities, institutional roles and working hours. Since their position involves daily encounters with the affected population, those street-level bureaucrats became sensitised and developed personal ties with the families. With limited staff and material resources, the social protection response in those subnational levels was highly dependent on the individual agency of bureaucrats and frontline workers and built through extra hours of work, creative action and emotional involvement.

Rio de Janeiro

- In comparison with Recife and Campina Grande, the services and policies targeted at the affected population rely more on informal networks, the agency of bureaucrats and frontline workers and the collaboration between them. Despite being reached by the epidemic later, when the causes of the neurological alterations were known, and after some of the guidelines from the Federal Government were already launched, both the state and the municipality of Rio did not develop coordinated actions at that moment in what concerns the social assistance field. The social assistance to the affected population was more demand-oriented/reactive in comparison to the services in Campina and Recife. Their actions were mostly in response to demands from the health sector and mainly focused on the access to social benefits (BPC).
- The fiscal crisis scenario, the austerity discourse and budget cuts left little room for manoeuvre to meet the needs of the virus-affected population. Local health and social assistance units were suddenly hit with demands to assist children with disabilities and social vulnerabilities that extrapolate their institutional capacities and responsibilities. In spite of this, the interviewees highlighted individual and collective initiatives at different levels in policy-making and implementation to cope with this new demand.

Recife and Campina Grande

- The geographic centre of the epidemic: both cities were at the core of the epidemic outbreak, where the first cluster of cases of alteration of epidemiological patterns in microcephaly was notified. Different than in Rio, Zika was portrayed as 'a problem of the Northeast', a region depicted in the national imaginary as a region-problem for its natural and socioeconomic conditions. The cities received lots of attention from the media (mostly Campina, for being the host city of Dr Adriana Melo, the obstetrician that first discovered the link between the Zika virus and microcephaly), were flooded with researchers, politicians, government and international organisations' representatives. This had also demanded officials' responses from government representatives (mayor, governors) and some political will into action.
- Besides, while in Rio some of the complex questions about the disease were known when the epidemic reached the territory, Recife and Campina had to provide quick responses to the epidemic 'on the making', without having any previous orientation from the Federal Government or answers to the many questions that had emerged. There was a shared notion of urgency among those working with the epidemic-related areas. The services were re-organised in a scenery of uncertainty, lack of knowledge, insecurity from the bureaucrats and frontline workers.
- As in Rio, actions from the social assistance sector in Recife and Campina were demanded by the health sector right after the outbreak of the epidemic, to help locate

the notified cases, refer them to the local health units and provide them access to social benefits (Active Search). The social assistance network was highly demanded at the beginning of the epidemic, in order to provide the affected families with social benefits, knowledge about their rights and psychosocial support. Currently, the social assistance network in both cities assists few families in the family care programmes (less than 10% of the confirmed) and work 'on demand', being activated according to the families' needs.

- Centro-Dia: Campina Grande was the first of the eleven cities that co-financed a Centro-Dia. Inaugurated at the end of 2017, the Centre aims at offering social and emotional support to the children affected by the Syndrome and their mothers. In Campina Grande, the Centre is located in an upper-class neighbourhood, in a big house, and employs professionals from different areas, such as therapists, psychologists, caretakers and social assistants. Among the activities conducted in the centre are group discussions, guidance to the families, counselling, and group and leisure activities. According to the municipal Secretariat, the Centre is a 'collective alternative of personal care, complementary to the families' care'.

3.3 Who is considered the 'targeted population' of social assistance policies?

- Vulnerability - A common point among those interviewed is the recognition that the social risks and vulnerability imposed by the disease classify those families as the 'targeted group of social assistance policies'. The socioeconomic conditions of the affected families, the extra and unequal burden imposed on mothers by care responsibilities and the social risks resulting from the disease were evident in all the discourses. Even among those who did not work on the frontline, the consequences of the syndrome were perceived as a sensitive issue, with severe impacts for the children and their caretakers. They also recognised the social, economic and emotional consequences imposed by the disease on the mothers, such the high cost of medicines; time-consuming rehabilitation treatments and the lack of information about future effects of the syndrome.
- The notion of vulnerability was related to gender roles and inequalities. This notion was constantly mentioned as a two-way process: while the Zika virus has mostly affected vulnerable women and families, it has also deepened their vulnerabilities and social risks. In this regard, the vulnerability was seen as more than economic deprivation, but as a broader facet that is affected by gender, living conditions, cultural practices and community relations. It conflicts, then, with the vulnerability notion by the Federal Government to the access to social benefits, based on strict and inflexible income criteria.

3.4 What is the relation between the local and national spheres? What are the conflictual dimensions, norms and guidelines that might differ in these different spheres?

- SUAS – Launched in 2005, the Unified System of Social Assistance (SUAS) organizes and funds social assistance services in Brazil based on a participatory and decentralized management model. All the federative entities are responsible for co-financing and coordinating social assistance policy in their respective areas. Services are provided by local facilities, namely the Social Assistance Reference Centres (CRAS) and Specialized Social Assistance Reference Centres (CREAS) at the territory level.
 - o As mentioned, the Federal Government launched some guidelines to state and municipalities concerning the Zika epidemic, but no extra budget was allocated to the municipalities or local facilities. The response was shaped as a way to include the affected population in the existing services.
- There was a shared perception that some policies and instructions from the Federal Government were delayed or inadequate in addressing the complexities of the syndrome. The interviewees pointed out some decisions that were distant from the real-life circumstances of the affected population, that might have hindered an adequate social protection response. In addition, it was alleged that instructions provided by the Ministry of Social Development were based on an idealised pathway towards the social assistance system that was inconsistent with the reality of the local units (CRAS) and municipal teams. The work conditions, material resources, human capital and infrastructure varies in each municipality and, in the case of Rio, were harshly constrained by the crisis
- Besides, the fiscal crisis and austerity narrative that has dominated official discourse since the *impeachment* of President Dilma, in 2016, has hampered access to social benefits. Despite budget cuts in social assistance services, the Federal Government has imposed additional controls and changed rules to make access to the benefits more difficult. The austerity narrative, aligned with a moral discourse to combat corruption, was also manifested in the ‘targeting’ controls imposed on social programme.
- The interviewed bureaucrats and frontline workers (both in Rio and in Recife) criticized the lack of flexibility in the income eligibility criteria to the BPC, despite the increase of the families’ expenses with medicines, treatment and special food (before 2016, the families were submitted to a social assistance analysis that could include extra expenses in the income eligibility criteria). Some also reported the difficulties into fitting the other manifestations of the Syndrome (that were not microcephaly) in the fixed categories of the registration form, what prevent physicians from providing the medical reports needed to access the benefit.
- Family Care - In the case of the families affected by the Zika virus, there is a shared notion that these services were not able to support families since mothers and children were already overloaded with the required health treatments and therapies. For

example, in Recife, only 7 out of 77 affected families are being assisted by those programmes. The recognition that the mothers will not have time to attend the meetings or to receive social workers at their homes was mentioned in most of the interviews in Rio, Recife and Campina Grande.

3.5 What are the integrated actions between social assistance, health and education sectors at the local level?

- A shared notion among those interviewed is that the response to the epidemic required an integrated approach, involving coordinated actions between the health, education and social assistance sectors. The epidemic has highlighted the lack of integration and the weaknesses and fragilities of public policies, including those targeted at people with disabilities.
- Despite the EAR guidelines, the integration of policies and services varied from place to place and involved different levels of coordination and cooperation among the state and the local bodies. In Rio, there was formal coordination among the state sectors (State Health Secretariat and State Secretariat of Social Assistance and Human Rights), what resulted in a joint technical note and a State Plan of Action. However, there was no similar coordination in the local/municipal level to meet the needs of the affected population. In Recife, a joint effort to coordinate the health and social assistance sectors to locate the diagnosed and suspected cases were made right after the epidemic, and a committee was installed to discuss the emergent actions, but the protocols and information flows were not codified in an official document. In Campina Grande, due to the political will and media attention, the education, health and social assistance sectors coordinated actions since the beginning of the outbreak.
- Redes de Inclusão (Inclusion networks) – Right after the outbreak, UNICEF gathered representatives from the health, education and social assistance sectors to develop protocols and capacity-building for managers and frontline practitioners in Recife and Campina Grande (the only municipalities of the pilot programme). This programme was mentioned by the interviewees as the main factor that led to an integrated action among health, social assistance and education sectors. The main goals of the Programme were to provide a methodology for early stimulation to be applied by mothers and caretakers at home (printed guides, videos and stimulation kits, made with cheap and reusable products), aligned with capacity building for health, education and social assistance professionals and the organisation of intersectional networks.
- Integrated actions versus definition of roles - Some interviewees mentioned the difficulties in defining the boundaries of each sector and their professionals' roles. This is due to the complexity of the disease itself, but also due to a public policy mindset in Brazil that prevent flexible roles and the interventions of one area into another. There

is some resistance in blurring those roles as well as some ambiguity in the definition of the 'integrated responses'.

- Families' Support Unit - At the state of Pernambuco, the social assistance sector has been involved in the coordinated talks with the state health secretariat since the outbreak of the epidemic, but most intersectoral action is done by the Families' Support Unit (*Núcleo de Apoio às Famílias*), established by the State Health Secretariat. This unit is composed by a coordinator in Recife and 12 regional assistants that are responsible for monitoring, support and information provision to the affected children and their families. Despite being professionals from the health sector, the assistants act in different areas, helping the families to meet their demands for medicine, treatment, education, social benefits. They work in between the state and the municipal levels, bridging the state and the citizens and coordinating actions from the health, social assistance and education sectors.
- Education - A growing demand is the inclusion of children in the education system, since they are now reaching schooling years. As far as I could research, there were no official guidelines, norms or even public debates about the inclusion of children with SCZ in nurseries and primary schools at the national level. Some explanations for this fact are: (1) in the Brazilian federative pact, nurseries are a municipal' responsibility; (2) the understanding that the inclusion of children with SCZ should follow the same procedures of any other children with disability, as stated at the National Policy for People with Disability; (3) uncertainties about the children's development and their ability to attend nurseries and schools in the near future; (4) the fact the demand for nurseries and schools emerged months after the outbreak, when the national and international attention had diminished.
 - According to the Brazilian Constitution, nurseries and primary schools are a municipal policy. The registration of students, selection and training of professionals, maintenance of facilities are dependent on the municipality action and, thus, varies considerably among different cities (although following standard procedures set by the Federal Government).
 - 14 children are attending nurseries in Recife and 8 in Campina Grande, which demanded the adaption and training of teachers, drivers and assistants. As in the case of social assistance, the interviewees conceived the response to the epidemic as a matter of inclusion in the existing policies. However, they also admitted that due to the severity of the disease some adaptation of services would have to take place (e.g., one caretaker per child instead of one per class).

3.6 What is the role of subjectivities, work conditions, moral values and pressures in the bureaucrats' decisions on social assistance policies?

- The fact that more than 90% of the interviewees were women is noteworthy. This resembles the gendered division in social assistance, education and primary care sectors in Brazil. Although it was not possible to identify a 'solidarity' discourse, some interviewees mentioned empathy as a driving force that compelled them into action, despite the adverse conditions. Most of the professional were mothers and some of the mother or grandmothers of children with some disability. Embedded in their discourse is the notion that 'they could be in their (the mother's) shoes', or that, for being mothers, they are able to understand and empathise with their suffering. There is also a shared feeling that the policy response is the result of the agency and activism of those professionals, that were able to build networks, find the gaps of a strict bureaucracy and ease the access to treatments and benefits, despite the political and economic constraints.
- At the frontline level, social workers from the health and social assistance units have established personal networks to instruct the families better and ease their access to social benefits. Some actions go beyond their assigned responsibilities, institutional roles and working hours. For example, the interviewees mentioned providing their personal contact information to the mothers; helping with appointments, documentation and requirements; creating informal networks among colleagues to prioritise access to services, and providing emotional and psychological support. Since their position involves daily encounters with the affected population, those street-level bureaucrats became sensitised and developed personal ties with the families. With limited staff and material resources, the social assistance response in Brazil was highly dependent on the individual agency of bureaucrats and frontline workers and built through extra hours of work, creative action and emotional involvement.

4. Publications and other works

BACHTOLD, Isabele. (2018) After Emergency: Social Protection Responses to Zika Virus in Brazil. Dissertation submitted in fulfilment of the requirements for the degree of Master of Arts in Development Studies.