



Ministério da Saúde

**FIOCRUZ**

**Fundação Oswaldo Cruz**



**The implementation of intersectoral actions of health and social assistance  
to assist children with Congenital Zika Syndrome in the State of Rio de Janeiro**

**Preliminary Report**

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**Introduction**

This study is part of the set of projects supported by the ZIKAlliance Social Sciences Research Group, the Oswaldo Cruz Foundation, which was established to investigate various historical, social and political realms of the Zika epidemic in Brazil. The study was conducted by researchers from the Public Policy area, the National School of Public Health, and the Fluminense Federal University to investigate the response of health and social assistance policies to the impacts of the epidemic, taking the case of the State of Rio de Janeiro.

The Ministry of Health and the Ministry of Social Development and Fight against Hunger launched the Rapid Action Strategy for Strengthening Health Care and Social Protection for Children with Microcephaly (EAR) to address the epidemic with a set of actions to be implemented by states and municipalities. The study sought to understand how this policy was implemented in the State of Rio de Janeiro. It aimed to analyse the process of implementation of the EAR in the State of Rio de Janeiro and the political and organizational context of the implementation of intersectoral actions; to identify successes and failures in intra and intersectoral coordination and cooperation; to analyse the elements of the implementation process that explain successes or failures of intersectoral actions.

With the end of the emergence of Zika cases in the country, attention focused on the implementation of strategies to ensure the strengthening of care actions for children with a confirmed diagnosis and the closure of cases that were still open.

This preliminary report provides a first overview of the issues discussed in the study. After the Introduction, we approached the characteristics of health and social protection policies, the study methodology, responses by public stakeholders, the context of Rio de Janeiro and the first results.

## 1. Background

In the second half of 2015, the unexpected impact of the Zika virus on pregnant women and their children, especially among low-income segments, soon evidenced the need for a comprehensive framework of actions that superseded the control of the *Aedes aegypti* mosquito and involved an extensive network of social services. In the face of the multiple social demands brought about by the syndrome, the need for acting in a rapid, intersectoral and coordinated manner was established for government agencies. Thus, a series of measures were taken by the Brazilian government, among them the National Plan to Combat Aedes and its Consequences.

The plan contained three lines of action, one of them being care, which provided for several actions to support children and their families. As a result of this plan, the Ministry of Health and the Ministry of Social Development and Fight against Hunger defined the Rapid Action Strategy for Strengthening Health Care and Social Protection for Children with Microcephaly (EAR), aimed at guiding the Unified Health System (SUS) and the Unified Social Assistance System (SUAS) to work together to track, diagnose and provide health care and social assistance for the affected children. This strategy required the joint action of health and social assistance policies to be implemented by the state level.

Intersectorality is a guideline advocated as a practical necessity since issues affecting the same population within a territory must be addressed by policies from different sectors. However, the integration or at least intersectoral articulation such as health and social assistance and these with other social areas such as education, health, housing and social security is hard to achieve. Several factors explain the problematic implementation of intersectoral actions, but one can highlight the centralized and sector-oriented tradition of the Brazilian bureaucratic structure, the ways of transferring resources between government levels of and the poor tradition of cross-organizational cooperation.

On the other hand, states coordination of intersectoral action is limited, given their role in the institutional arrangement of health and social assistance policies. Both policies are decentralized and provide for shared responsibility between levels of government, but the mechanisms of coordination and cooperation between the bodies involved are fragile, hindering the integration of service networks, optimized resources and shared funding.

The state of Rio de Janeiro has already faced several outbreaks of diseases, including dengue, related to *Aedes aegypti*. In the case of Zika, it is the third state in the country in confirmed cases of children with neurological changes possibly related to Zika virus infection and other infectious aetiologies between 2015 and 2018<sup>1</sup>. The state has a tradition of public health and social assistance, with a vast network of public services, especially health, universities, university hospitals and research centres, since the capital of the state, Rio de Janeiro, was the capital of Brazil until 1960. In the study period, the state faced a severe economic crisis, which would make the challenge of coping with the epidemic even greater.

Faced with an acute crisis of a hardly known epidemic, where policies had to respond quickly, effectively and jointly, it was interesting to know how an intersectoral strategy in the area of health and social assistance mobilized actors,

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<sup>1</sup> Brasil (Ministério da Saúde) [homepage na internet]. Boletim Epidemiológico. Vol. 49. N46, nov, 2018.

created institutional mechanisms and networks to assist affected children. Thus, from a public policy perspective, it was intended to identify not only the problems of the implementation process but alternatives both for the support needed to the future consequences of the epidemic and learning in the implementation of social policies.

## **2. Organization of social protection policies: health and social assistance**

The health and social assistance policies underpin the welfare system, which is called social security in Brazil. In particular, health and social assistance policies have suffered profound changes in the last decades, starting with the Federal Constitution of 1988. Health became universal and comprehensive, and the Unified Health System (SUS) was created. This unified system is decentralized, with shared responsibilities between the three levels of government – federal, state and municipal. The concept on which federalism is based in the social area is that of cooperation between levels of government. This cooperation, however, has been quite problematic, for several reasons. Brazil is a federative country with three levels of government – federal, state and municipal – with reasonable autonomy in the definition of their social policies. There is a great deal of inequality between states and municipalities regarding financial and bureaucratic technical capacity. The SUS suffers from chronic underfinancing, leading to fierce disputes over resources, and political differences among federal entities also prevent cooperation. These difficulties are reproduced to some extent also within each level of government, since fiscal restrictions usually affect social areas, hampering intersectoral cooperation.

Social assistance follows the same organizing logic of the health policy. It is governed by a unified national system (Unified Social Assistance System - SUAS), decentralized and accountable to the three spheres of government. It is a weaker area in the state structure since it has only recently been established as public policy. Historically, social assistance has had very low institutionality, with targeted, discontinuous programs and actions, often of a charitable and clientelistic nature.

The social assistance policy is aimed at the vulnerable segments, where family, community and the territory are target areas for defining actions and services. Social assistance services are organized into two levels of complexity - primary and special social protection. Primary social protection provides regular services to families and individuals in situations of vulnerability and special social protection covers situations of violation of rights (violence, abuse or sexual exploitation, abandonment, disruption or compulsory separation from the family). The service network consists of facilities distributed by complexity and type of service. In the case of facing the epidemic, the Social Assistance Reference Centres (CRAS) and Day Centres are the main establishments.

The CRAS are primary social protection facilities installed by population criteria and in areas of higher social vulnerability. The last official social assistance survey returned 8,292 CRAS in the country, of which 442 in the state of Rio de Janeiro. As a gateway to social assistance services and benefits, they were an essential vehicle of the “Rapid Action Strategy” for the active search and orientation of pregnant women and households, as well as for expediting receipt of the Continuous Cash Benefit (BPC), constitutionally guaranteed to disabled people (and also older adults) with family income up to 1/4 of the minimum wage.

Day Centres are establishments that already served young people and adults with disabilities in a situation of dependency, and started to attend children with microcephaly after the epidemic. In Brazil, 1,163 Centres were servicing children with disabilities in 2017, of which 93 in Rio de Janeiro<sup>2</sup>. It is not possible to identify which ones provide treatment to children with Zika-related congenital syndrome. However, it is assumed that this number is small since most lack equipment and especially a sufficient number of qualified professionals to address this complex syndrome.

In social assistance as in health care, municipalities are responsible for the direct provision of services, and they must be technically and financially backed by the states. However, state action has been weak both in financing and in technical support and capacity building to municipalities, which aggravates the inequity between them. In health care, municipalities bear most of the costs and states generally do not comply with the minimum requirement to participate in the financing. In social assistance, where there is no mandatory minimum, most of the funding is still at the federal level, due to the resources of Bolsa Família (*Family Grant*) and BPC. However, municipalities have increased their participation in the provision of care services.

One of the significant obstacles to the expansion of social areas is the statutory limit on personnel costs. The federal government, states and municipalities cannot exceed the established percentages of their budgets, which restricts the recruitment of servants. Thus, it has become common to outsource professionals hired through companies, generating a high turnover of professionals and differentiated salaries for similar services, which compromises the adherence of professionals, and consequently the quality of services. In Rio de Janeiro, this problem has deteriorated and was pointed out as one of the difficulties for intersectoral action.

The health sector's service network is organized by levels of complexity, with primary care being the preferred system's gateway. Medium and mainly high complexity care is concentrated in larger municipalities or metropolises, which requires hierarchical and organized networks according to health regions. This function is best performed by the states, which agree with municipalities to provide services as per installed capacity in the region. That is why states were a priority in the EAR.

The design of social policies in Brazil provides for the need for cooperation and coordination among them but does not establish mechanisms to achieve this. The problem can be attributed to: a) sectionalisation resulting from the financing structure, which combines resource linkage with low funding; b) the difficulties arising from the federative pact and the decentralized social policies, which hinder relationships between the three levels of government. These aspects are reflected in the bureaucratic structure, hindering or delaying intersectoral initiatives.

### **3. Methodological Approach**

The literature points out that intersectoral actions require reasonable levels of cooperation and coordination to be effective. Two major issues for the implementation of policies from different sectors, but targeting the same population, are coordination and cooperation between organizations. Problems in

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<sup>2</sup> Brasil (Ministério do Desenvolvimento Social) [Internet homepage]. Vigilância Socioassistencial [Access on Feb 01, 2019]. Available from: <http://aplicacoes.mds.gov.br/snas/vigilancia/index2.php>.

operationalizing these two components of policy management between different sectors undermine the quality of public services and the quality of life of people in need of care and social protection.

In the political theory, these issues that public policy must address are seen as a problem of collective action<sup>3,4,5</sup>, whose response depends on mechanisms of cooperation and coordination, without which it is unlikely to achieve sustainable results<sup>6,7,8</sup>.

In the case of policies or programs with interfaces in different sectors, coordination and cooperation are even more crucial to the achievement of results. These issues guided data collection and analysis. These issues guided the data collection and analysis of the implementation of health and social assistance actions concerning babies born with Zika Syndrome in Rio and Janeiro, based on the following analytical categories:

**Intersectoriality: Relationships between different policy sectors.** The intersectoral action by the State is a form of intervention based on the joint action for the formulation and implementation of policies or programs of different sectors, focusing on the specific needs of particular target groups.

In the health sector, the institutionalization of social security in Brazil has made the relationship between health problems and their social determinants more evident, paving the way for the formulation of intersectoral policies. Healthcare has come to be seen as the result of a set of variables that are not limited to the provision of medical care and rely on meeting the needs external to health itself. The high inequality and vulnerability of individuals and households that characterizes Brazilian society limit the effectiveness of health care.

In social assistance, intersectoriality is one of the main guidelines, since its guiding principle is to ensure social rights, not just provide services and benefits. Part of the work of the network of social assistance services is to guide, refer and monitor users in their social needs, which often depend on other sectoral policies. Thus, care workers, especially social workers, are trained to seek mechanisms of intersectoral action with areas such as education, healthcare, housing, and social security. However, since it is an area whose institutionalization is most recent among universal social policies, social assistance faces hurdles to joint action with traditional sectors such as education and healthcare and welfare.

**Coordination:** decisions and actions by one or more actors seeking to ensure that the various organizations involved in providing some public service together do not produce redundancies or gaps. Coordination mechanisms facilitate the

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<sup>3</sup> Olson, M. *The Logic of Collective Action*, Cambridge MA: Harvard University Press. 1965.

<sup>4</sup> Elster, J. *The Cement of Society*, Cambridge University Press. 1989.

<sup>5</sup> Gillinson, S. *Why Cooperate? A Multi-Disciplinary Study of Collective Action*. Overseas Development Institute. London. 2004.

<sup>6</sup> Polski, M.M & Östrom, E. *An Institutional Framework for Policy Analysis and Design*. Workshop in Political Theory and Policy Analysis. Indiana University. Bloomington; 1999. Workshop Working Paper Series no. W 98-27.

<sup>7</sup> Östrom, E. *Understanding Institutional Diversity*, Princeton University Press. 2005. Princeton.

<sup>8</sup> Östrom, E. *Analyzing Collective Action*. Arizona State University. 2009. Tempe.

adjustment of intersectoral policies and programs to increase their horizontal interconnections, with the possible sharing of financial sources.<sup>9,10,11</sup>

**Cooperation:** it is the joint action of a group of individuals to achieve a common goal<sup>12</sup>. It is an interaction between individuals or sectors to achieve greater efficiency in their actions, optimizing resources with the establishment of more or less formal relationships. Information sharing is the first step towards cooperation<sup>10,11</sup>.

**Networks:** horizontal interactions between state stakeholders or civil society that address specific policy issues and policy processes. In contemporary democratic societies, public policy management ceases to be vertical and hierarchical because the ability to find solutions to problems transcends sectoral boundaries and encompasses various subsystems and political spheres. Policy governance occurs through horizontal, complementary, decentralized structures. Networks are a fluid structure of horizontal, decentralized, informal relationships that become part of governance.<sup>13</sup>

### 3.1.1 Investigation methods and techniques

Considering the aspects imbricated to the central issue of the research, that is, how the state of Rio de Janeiro organized to ensure, in an intersectoral way, health care and access to social assistance policies for children affected by Zika Congenital Syndrome (ZCS), the research team developed fieldwork based on interviews with managers and professionals of social assistance and health secretariats of the State of Rio de Janeiro. We also conducted interviews with some municipal managers to gain a better understanding of the problems faced by the local implementation.

In this process, we consolidated a total of 16 interviews with key actors who work in the following bodies<sup>14</sup>:

- **Ministry of Health:** the respondent worked at the institution at the time of the epidemic and followed the establishment of coordination strategies by the agency.
- **Fernandes Figueira Institute (IFF/Fiocruz):** three people were interviewed at this institution. These interviews were essential and enabled us to understand how care and initial diagnoses were provided to the children and their families in the state of Rio de Janeiro.
- **State Health Secretariat of the state of Rio de Janeiro (SES):** four people were interviewed. All held management positions, but with different functions. Three people were interviewed at the

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<sup>9</sup> Peters, G. Managing horizontal government. The politics of coordination. RESEARCH PAPER No. 21 Canadian Centre for Management Development. Canadian Centre for Management Development. January 1998.

<sup>10</sup> Solar O; Irwin A.A Conceptual Framework for Action on the Social Determinants of Health. Discussion Paper 2 . World Health Organization. Geneva 2010.

<sup>11</sup> Rantala, R. Bortz, M. and Armada, F. Intersectoral action: local governments promoting health. Health Promotion International, Vol. 29 No. S1. 2014.

<sup>12</sup> Gillinson, S. Why Cooperate? A Multi-Disciplinary Study of Collective Action. Overseas Development Institute. London. 2004.

<sup>13</sup> Silke Adam and Hanspeter Kriesi, "The Network Approach", in Theories of the Policy Processes, ed. Paul Sabatier, Westview Press, Boulder Colorado, 2007.

<sup>14</sup>. The interviews were conducted from October 2017 to September 2018.

Superintendence of Primary Care, and one at the Superintendence of Specialized Care, Control and Assessment (SAECA).

- **State Social Assistance and Human Rights Secretariat:** an interview was conducted with one manager who participated in the articulation process with the State Health Secretariat of the state of Rio de Janeiro, in the construction of coordination and cooperation strategies.
- **Sub-secretariat of Social Assistance and Management Decentralization of the State of Rio de Janeiro (Sectids):** Two interviews with technical advisors, one of the Primary Social Protection and one of Line II of the EAR, responsible for the articulation of social assistance to other social policies.
- **Department of Social Assistance and Citizenship of the municipality XX:** Three people were interviewed. They are respectively the Secretary of Assistance, the Coordinator of Primary Protection and one social worker working at the Reference Centre for Social Assistance (CRAS) of the municipality.
- **State Brain Institute (IEC):** Two people were interviewed. Both work in the Zika Project. They have been working at the institution since the onset of the epidemic until now, in which new diagnoses are being carried out on the cases that had been discarded in that period.
- **Municipal Health Secretariat of Rio de Janeiro:** An interview was held with one professional who held a management position at the onset of the epidemic.

The choice of institutions and professionals took into consideration their involvement, outlined in the ministerial orders, as well as their role in health and social assistance policies. Several respondents in the research were indicated by stakeholders previously interviewed, using the snowball technique. Considering the expertise and the performance of some people with the ZCS problem at the time of the outbreak and in the post-epidemic period, the professionals indicated key individuals that were of paramount importance for data consolidation.

Different interview roadmaps were elaborated considering the needs and objectives of the research. Professionals working in management positions answered some specific questions, and professionals working in technical areas or other spaces that work directly with children and families answered other questions. Roadmap differentiation was necessary so that the professionals could delimit in their statements the specific aspects of their performance.

In the field research process, face-to-face interviews by all team members, or by at least two people were prioritized. Only one interview was conducted via Skype because the professional worked at the Ministry of Health and resided in the city of Brasília.

In addition to conducting the interviews, the research team also participated in two meetings that were held by the Line II Steering Committee and which involved

professionals from various institutions in the state of Rio de Janeiro. These consisted of managers or officers from municipalities, from state and partner institutions, such as Fiocruz, the Fernandes Figueira Institute, and the State Brain Institute (IEC).

The team also participated in academic events and policy meetings on the consequences of the epidemic, some with the participation of mothers and families, that were essential for the construction of the results.

The consolidation of the analysis of these interviews and the elements analysed in the official documents - such as ministerial orders, legislation and other aspects that permeate the field of coordination and cooperation - have taken place from the transcripts and analysis tables constructed periodically by the team.

We focused on the following issues concerning the coordination and cooperation between health and social assistance.

- The existence of coordination mechanisms:
  - Who coordinates? How is coordination performed?
  - Mechanisms explicitly defined in policy tools (EAR, etc.);
  - Sharing of financial sources;
  - Knowledge, in each organization, of the activities of other organizations;
  - Communication channels between organizations and actors;
  - Monitoring procedures and their levels;
  - Shared information;
  - Shared resources;
  - Communication channels between the actors and organizations involved;
  - Formal and informal relationships;
  - Active search for diagnosis or treatment;
  - Transportation;
  - Housing when the diagnosis is made outside the home;
  - Medical diagnosis/report;
  - Definition of reference services and flows for access;
  - Referral to different services: communication channels.

#### **4. The national response to the epidemic: a brief description**

In the first semester of 2015, cases of “exanthematic disease from ill-defined causes” began to be observed in the North-eastern region of Brazil, in the states of Bahia, Maranhão, Pernambuco, Rio Grande do Norte, Sergipe, and Paraíba. The growing number of cases of microcephaly recorded in Pernambuco from August of that same year led the State Health Secretariat to request the support from the Ministry of Health for the analysis of what was considered a rare event in the state at the time. In November, the relationship between *Aedes aegypti*-borne Zika outbreaks and cases of microcephaly was noted. In states such as Ceará, Rio Grande do Norte and Paraíba, signs of the relationship between infection by this etiological agent and fetuses with microcephaly were found, besides the identification of deaths in infants with the same malformation.<sup>15</sup>

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<sup>15</sup> Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Vigilância das Doenças Transmissíveis, Departamento de Vigilância das Doenças Transmissíveis. – Brasília: Ministério da Saúde, 2015. 55p.: il. Modo de acesso:

In November of 2015, in the face of national turmoil and deterioration of the epidemiological situation caused by the increased number of children born with encephalic disorders, especially in the Brazilian Northeast, the MoH declares an Emergency Public Health Situation of National Importance (ESPIN). Thus, a series of surveillance, prevention, and assistance initiatives are developed. The Centre for Emergency Public Health Operations (COES) is established as a management and coordination mechanism to respond to this occurrence as per international health regulations<sup>16</sup>. In December, when the circulation of the virus had already occurred in eighteen states of the country, the Ministry of Health launched the “Protocol for Surveillance and Response to the Occurrence of Microcephaly Related to Zika Virus Infection”.

The first intersectoral initiatives to confront the epidemic from the Ministry of Health occur amidst a situation of worsening economic and political crisis of the government of President Dilma Rousseff, which ends with its impeachment in August 2016. Again in December 2015, the National Plan to Combat *Aedes* and its Consequences, with three lines, involving 19 bodies entities is launched<sup>17</sup>.

Line 1, which covers mobilization to combat the vector, consisted in the organization of coordination and control rooms at the federal, state and municipal levels and aimed to reduce *Aedes aegypti* infestation, implement local actions of communication and visit to households, among others.

Line 2, which covers care, included the mobilization of public laboratories for diagnosis; publication of health care protocols for microcephaly; guidelines for early stimulation with guidance to teams for the care of children with microcephaly (January 2016); preparation of the Handbook for Families and Caregivers for early stimulation and the Guide for Primary Care Professionals; qualification of professionals; active search of families of children reported as suspected cases; construction of a System of Registration of Care for Children with Microcephaly – SIRAM, which was expected to be used by April 2016. Our study focuses on this line.

Line 3 focused on technological development, education and research, with the funding of several lines of research and the participation of development institutions and research institutes.

In order to standardize assistance to affected children, in March 2016, the Ministry of Health and the then Ministry of Social Development and Fight against Hunger published Interministerial Order N° 405, establishing the Rapid Action Strategy for Strengthening Health Care and Social Protection for Children with Microcephaly (EAR)<sup>18</sup>. Two weeks later, the Joint Operational Instruction (31/3/2016) was published to guide the operationalization of the actions to SUS and SUAS managers.<sup>19</sup>

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www.saude.gov.br/svs

<sup>16</sup> Brasil. Portaria n° 1.813/GM/MS. 11 nov 2015.

<sup>17</sup> Brasil (Ministério da Saúde) [homepage na internet]. Dengue, Chikungunya e Zika. [access on Feb 01, 2019].

Available from: <http://combateaedes.saude.gov.br/en/national-plan>.

<sup>18</sup> Brasil (Ministério da Saúde e Ministério do Desenvolvimento Social e Combate à Fome). Portaria Interministerial no.405. 15 mar 2016.

<sup>19</sup> Brasil (Ministério da Saúde e Ministério do Desenvolvimento Social e Combate à Fome). Instrução Operacional Conjunta N° 2. 31 mar 2016.

EAR involved the Unified Health System (SUS) and the Unified Social Assistance System (SUAS) and had two main objectives. Before the enormous lack of knowledge about the epidemic and its different forms of manifestation, the first objective was to seek to step up the process of knowledge and diagnosis to refer the affected children to care quicker. The other objective was to support families and to refer those who were within the income profile quicker to access the Continuous Cash Benefit (BPC)<sup>20</sup>.

The strategy required coordination in planning and managing the central levels – besides the federal government, states and municipalities – and cooperation between service units at the local level in the implementation of health care and social assistance.

In the SUS, the ordinance guided the determination and identification of suspected microcephaly cases reported as “under investigation” and “investigated and confirmed”; the active search, the transportation and lodging of the child and family member when outside their home until the service assigned to clarify the diagnosis and return to the origin; the confirmation of the diagnosis of the cases; the provision of full paediatric clinical assessment of the child; the provision of a detailed medical report with the necessary minimum information on the diagnosis and clinical condition of the child, in order to plan the care and to instruct the process of granting the Continuous Cash Benefit (BPC); the definition and referral of each child with microcephaly to the most appropriate services, early stimulation and specialized care, as per the healthcare protocols established by the Ministry of Health.

In the SUAS, the Order guided the collaboration with the SUS network in the active search of suspected cases of children with microcephaly and their families; and the provision of social services and benefits to children with microcephaly and their families.

The structuring of the healthcare network, the definition of referral services and flows for the access of both suspected and confirmed cases of children with microcephaly at all the planned stages of the EAR was incumbent on the state, district and municipal managers of SUS and SUAS. The state managers of the SUS, in agreement with the municipal managers in the Bipartite Interagency Committees (CIB)<sup>21</sup>, should define the health establishments authorized to issue detailed medical reports with diagnoses for eventual investigation of the process of granting the BPC.

In total, R\$ 10.9 million (around 2.5 million dollars) were invested in the EAR. The state governments should receive R\$ 2.2 thousand (around US\$ 550) per suspect case reported. In partnership with municipalities, they should carry out the active search, transportation, lodging and imaging diagnosis of the children.

The lack of knowledge about the epidemic and the possibility of the birth of an entire generation of children with severe neurological alterations, especially

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<sup>20</sup> Income transfer benefit of the value of a monthly minimum wage for disabled people (and the elderly) with per capita family income up to ¼ of the current minimum wage.

<sup>21</sup> Committees composed by State and Municipal authorities to discuss and make agreements on the management of policies and services. They are part of the Brazilian health and social care systems and the main mechanism for integration between the two levels of government (State and Municipality).

among the poorest segments of the population, was a decisive factor for the intense mobilization of stakeholders from different societal segments and spheres.

Notification was one of the first bottlenecks to be overcome, but with the outbreak of the epidemic, the notification criteria were not clear either. Initially, reports were based on head circumference but faced with different neurological manifestations during the development of the children, other criteria were being defined, new classifications were being built, which affected the records and construction of the information system that gathered data on microcephaly, namely, the SIRAM.

There was a whole work of cooperation and guidance of the Ministry of Health concerning the services of the health care sector. In the Northeast, the MoH mobilized university hospitals that became reference points to attend, make tests and diagnose the children in a single day, sparing inland dwelling families the many back-and-forth travelling days.

One of the most significant problems in health care is children who do not live near specialized rehabilitation centres. The Family Health Support Centre in the territory was defined with the objective of promoting the early stimulation and the follow-up of the development of the affected children. The MoH transferred resources to the municipalities to acquire kits of early stimulation, and in conjunction with the states, children re-evaluation protocols were defined during their development.

The nature of the epidemiological and healthcare crisis required coordinated governance that involved not only the federative entities but also multilateral organizations and national and international research institutions. Several networks were set with different stakeholders, sectors and spheres of action. In the area of health, the National Network of Specialists in Zika and Related Diseases (Renezika) was established to support the Ministry of Health with research information related to the Zika virus and related diseases in various spheres – surveillance, prevention, control, social mobilization, health care and scientific and technological development<sup>22</sup>.

Several initiatives by federal officers were taken to understand the disease, seeking to bring closer and articulate studies that would allow advancing studies on the development of the syndrome in children. A consortium was created to establish a link between studies of different cohorts and the construction of the network on time made facilitated the cooperation between different organizations and research institutions.

Strategies regarding states and municipalities followed the traditional public health actions, mobilizing partners through meetings, visits and videoconferences involving the various states coordination offices for children, primary health care and health surveillance.

With the decreased number of cases and some advances in knowledge about the causes and transmission mechanisms of Zika, the Zika and Microcephaly Public Health Emergency was suspended in May 2017. Under President Michel Temer government, changes in the technical teams of the various ministries involved hindered coordination and disrupted ongoing cooperation processes.

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<sup>22</sup> Brasil. Renezika [internet homepage]. [Access on Feb 01, 2019]. Renezika. Available from: <http://renezika.org/portal/>.

Discontinuity was not only at the federal level since the decision to end the emergency coincided with the municipal elections. With the inauguration of new mayors in January 2017 and change in teams, many municipalities had to start over from scratch, interrupting processes already underway.

The end of the emergency alone meant the reduction of resources and activities. However, as universities, research institutes, societies and associations, services of different specialities had been mobilized, interest in studies on the dynamics of the epidemic and its consequences remained. Microcephaly was no longer mentioned, but a congenital syndrome, since many children with the head circumference within accepted parameters had other neurological alterations. Between the onset of the emergency and November 2018, 16,735 suspected cases of “developmental and growth alterations possibly related to ZIKA virus infection and other infectious aetiologies” were reported to the Ministry of Health<sup>23</sup>.

## **5. The case of the state of Rio de Janeiro**

Between the onset of the epidemic in 2015, and until October 2018, in the state of Rio de Janeiro, 12,190 pregnant women were reported with the presence of the Exanthematic Syndrome, where 16.5% were positive for Zika Virus. During this period, the State Health Secretariat informed the federal government of the existence of 1,093 suspected cases of children born with microcephaly. In total, 470 cases were discarded, 340 were confirmed and 248 cases were under investigation<sup>24</sup>.

The State of Rio de Janeiro (ERJ) has around 17.2 million inhabitants, distributed in 92 municipalities with significant inequalities in the access to health services, of which 66 had children with suspected cases of ZCS<sup>22</sup>.

The suspected cases were referred to the State Brain Institute (IEC), which was responsible for the diagnosis of children with microcephaly in the State. The evaluation of these children was carried out in three stages. The first consisted of a multidisciplinary visit (paediatrics, social assistance, speech therapist, neurologist and psychologist) with children and their families. The children were then referred for complementary examinations (CT scans, resonances, etc.). Finally, the IEC provided the families with the reports of the tests performed, answered all the questions, and guided the follow-up services that had to be performed in the municipality of origin of the child, which had to integrate it into the network and define care flows.

Data from the Ministry of Health<sup>1</sup> show weaknesses in the follow-up of these children after confirmation of diagnosis in the ERJ. Only 42.3% of children carry out childcare, 36.4% have access to specialized care, and only 2.7% undertake early stimulation.

The 1988 Federal Constitution defined for state governments a role of coordination and planning of health policy rather than as executor of actions that is the responsibility of municipalities<sup>25</sup> (Silva & Labra). In Rio de Janeiro, however, given the wide network of existing state services and the difficulty of

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<sup>23</sup> Brasil (Ministério da Saúde). Boletim Epidemiológico vol 49, 46, 2018.

<sup>24</sup> Rio de Janeiro. Secretaria de Estado de Saúde do Rio de Janeiro. Informe CIEVS 009/2018.

<sup>25</sup> Silva, Ferreira Ionara & Labra, Maria Eliana. As instâncias colegiadas do SUS no Estado do Rio de Janeiro e o processo decisório. *Cadernos de Saúde Pública* 17 (1): 161-170 jan/fev 2001.

overcoming political issues for the implementation of decentralization, the state body accumulates a dual role of provider of various services and health manager.

The main intersectoral guideline document at the state level is Joint Note N° 001 of July 1, 2016, prepared by healthcare and social assistance managers, which established the guidelines for the creation of the Municipal Situation Room in order to follow the notified cases and those underway. Coordinated by the Superintendence of Primary Care of the State of Rio de Janeiro, it consisted of several stakeholders of the two policies. To that end, each municipality should appoint a professional responsible (focal point) for social assistance and for health care that should centralize information on the follow-up of the children in their territory. The measure required professionals to be knowledgeable about the network and with the ability to collect the necessary data, define care strategies and articulate the services.

The healthcare focal point received the reports of suspected and confirmed cases and requested the services in their territory to enter confirmation/exclusion data of cases and follow-up in childcare, early stimulation, specialized care or death. The social assistance focal points supported CRAS in the active search of children diagnosed with ZCS received from PHC and the articulation with social assistance services and the health focal point to follow the care provided to these children. The data collected were informed to healthcare and social assistance managers to monitor the quality of care provided.

From these data, the Situation Room established strategies to close the cases and ensure the follow-up of these children through healthcare and social assistance. During this period, several meetings were held at the health secretariat and with the social assistance secretariats to exchange information and define strategies to support municipalities to ensure their access to social protection services and, in the case of children living in extreme poverty, ensure access to the Continuous Cash Benefit.

Despite the initial hardships in defining these professionals, all municipalities had defined their focal points by the end of 2016<sup>26</sup>. However, the economic and political crisis suffered by the state of Rio de Janeiro and the municipal elections, with the replacement of several rulers, led to discontinuity of the focal points and the need to restart the whole process of articulation and awareness of the municipalities.

In spite of the difficulties experienced by the state body to play its coordinating role, an institutional learning is observed in this period, expressed in the efforts to maintain the Situation Room after the emergency has been withdrawn by the federal government, aiming at discussing cases, developing strategies of actions to improve the health care provided to the children and expanding partnerships with other secretariats and education-research institutions that are dedicated to the topic of ZCS.

In December 2017, the Ministry of Health, through the Ministerial Order 3.502 launches the *Strategy to Strengthen Actions of Care for Children Suspected or Confirmed for ZCS and other syndrome provoked by syphilis, toxoplasmosis,*

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<sup>26</sup> Rio de Janeiro. Comissão Intergestores Bipartite - Ata da 12ª Reunião Ordinária dez/2016.

*rubella, cytomegalovirus and herpes virus*. The objective of this order was to support, through financial incentives, the states and the municipalities in the organization of laboratory and clinical diagnoses as well as comprehensive care for children affected by these syndromes.

Based on that order, the State Department of Health of Rio de Janeiro approved in June 2018 the *State Plan for the Execution of the Strategy to Strengthen Child Care Actions Suspected or Confirmed by SCZ and STORCH*. The Plan was settled to cope with several difficulties experienced by the State during the epidemic, mainly: production and diffusion of reliable information, the role of the focal points, transportation of children for out-of-town treatment, the flow of services and demanded intersectoral actions. In addition to improving care for the children, the aim is to reduce the high number of children with diagnoses still open. The strategies designed by the Plan are based on a set of macro-actions and actions to be developed until 2019 through intersectoral actions. It defines responsibilities and establishes monitoring indicators. The final version of the document was prepared after the presentation to the municipalities for validation and suggestions.

## **6. Preliminary results:**

Cross-organizational conflicts: There is reasonable order autonomy of some of the institutions and services involved in coping with the epidemic, either because they are research institutions or services, which have a great ability to raise funds and therefore have power and prestige, or because they belong to different levels of government. Although all were highly committed to coping with the epidemic, cooperation and the role of the state manager in coordinating actions were compromised. In the case of research institutions, there were also disputes over the primacy of the analysis of the event of the epidemic, which may also have influenced cooperation initiatives.

Intraorganizational conflicts: These conflicts were identified mainly within the state health structure, attributed in part to the political and financial crisis experienced by Rio de Janeiro. There was little adherence of the state government to the epidemic problem, and the managers of health and social assistance secretariats had to take the responsibility for implementing the necessary measures with the municipalities, with few financial and human resources.

The leading role of professionals and managers: Given the difficulties of coordination of the service network and the lack of intersectoral mechanisms, many of the actions implemented depended on the individual initiative of managers and professionals, through the creation of interpersonal networks, generating cooperation. This “informal” cooperation operated among public organizations, allowing some degree of coordination between public services. The implementation of cooperation occurs bottom-up, where the actors involved seek to build a cooperative context in a horizontal relationship.

Role of agreement levels: Bipartite interagency committees (CIBs) were an essential channel between state level and municipalities and showed the state health and social assistance secretariats initiative for coordinating actions, with dissemination and orientation for emergency measures (focal points, protocols, referrals), but were limited by the restriction and instability of financial and human resources.

Impacts of high turnover among officers: the temporary recruitment of professionals and officers (either by outsourcing services or through political indication positions) generates a high turnover in the management of services, with disrupted and discontinuing actions. This was significant for the focal points, PHC and social assistance managers in the municipalities due to the change of municipal governments in January 2017, as well as in the health and social assistance secretariats of the state of Rio de Janeiro.

Lack of awareness and controversy over the disease: uncertainties about the consequences of the epidemic led to uncertainties about the procedures, especially on the healthcare protocol, which required changes in the conduct of actions by states and municipalities.

Advocacy and support networks: At the initiative of groups of mothers in association with research institutions and services, networks have been created to claim services for children with the syndrome. These networks have led to the creation of support structures for families, the dissemination of children's problems and demands, the holding of public hearings and the participation of public prosecutors in the coordination of the service network.

Preliminary conclusion: the implementation of intersectoral healthcare and social assistance actions where it occurred depended more on the informal cooperation initiative between public agents than on formal policy mechanisms. Care protocols for diagnosis and follow-up of confirmed cases, information networks and mechanisms for monitoring actions in municipalities have been established. However, there was a lack of coordination of the service network, due to the decentralized structure of health and social assistance systems, the lack and poor quality of services in municipalities, and unstable financial and human resources. Child and family care services remain weak and of poor quality and there is no total control over the ill-defined cases.

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