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Profile of demand and Continuous Cash Benefits (BCP) granted to children diagnosed with microcephaly in Brazil

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Abstract *The Brazilian Federal Constitution of 1988 introduced the Continuous Cash Benefits (BCP), allowing the inclusion of people with disabilities. This is a descriptive study with aggregate municipal data about the time and geographic distribution of the incidence of microcephaly related to the Zika virus in Brazil and data of the BCP grants to children diagnosed with microcephaly. Data on the demand and BCP grants to children with microcephaly since 2009 are shown. Cases of microcephaly and/or central nervous system disorders were obtained from the Ministry of Health and totaled 2,366 confirmed cases from January 1, 2015 to December 31, 2016. The historical series of BCP granted from 2009 to 2016 was based on data from the National Institute of Social Security and showed, until 2014, a baseline with an average of 200 annual benefits for children younger than 48 months with microcephaly. In 2016, grants increased eight times, reaching 1,603 benefits granted to children of 731 municipalities spread in the 27 States. The Northeast accounted for 73% of the BCPs granted, however, this was less than 65% of the demand for incident cases. The implementation of the integrated referral system, including active search, should be strengthened to ensure access to all children entitled to BCP.*

Key words *Microcephaly, Zika virus, Children*

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Introduction

This paper aims to show data on the demand and grant of the Continuous Cash Benefits for children with microcephaly in the national territory since 2009. From this data, we intend to provide subsidies to work on effective actions to ensure a network of social protection for children with microcephaly and their families. Undoubtedly, the consolidation of actions and services for this population permeates different spheres of state organization, among them health and welfare.

The Federal Constitution of 1988 introduced, in the article that addresses the social welfare policy (Article 203), a guarantee of a minimum wage for people with disabilities and elderly people who do not have the means or family conditions to cater for their own livelihood. This benefit was established by the Social Welfare Organic Law (LOAS) N° 8.742/93¹ and named as Continuous Cash Benefit (BPC). The prerequisite for granting BPC is per capita household income of at most ¼ minimum wage and proof of disability or age over 65 years.

This is a benefit of the social welfare policy, managed by the Ministry of Social Development (MDS), and its operationalization is carried out by the National Institute of Social Security (INSS). In cases of disability, the INSS evaluation goes through an administrative stage, where the household income is calculated and later submitted for technical analysis for the characterization of disability. Since its regulation by Decree N° 1.744 in 1995, BPC grants for persons with disabilities (PwD) have undergone changes, especially in line with the national policies in place for this population².

In 2009, the BPC's evaluation process undergoes a transformation and is now based on the International Classification of Functioning, Disability and Health (ICF)³, along with the Convention on the Rights of Persons with Disabilities⁴ as a horizon. Therefore, the International Classification of Diseases (ICD) is no longer the sole criterion for granting the benefit. According to the evaluation proposed by Joint Ordinance MDS/INSS N° 1/2009 and Joint Ordinance MDS/INSS N° 1/2011, the disability is submitted to a medical and social assessment, thus ensuring the recognition of the complexity of the disability and the importance of interaction of individuals with disability, their family and the society in which they are inserted⁵.

Currently, the concept of disability used is that described in Law N° 8.742/93, ratified by

Law N° 13.146, of July 6, 2015 (Brazilian Law of Inclusion): *a person with a disability is one who has long-term impediments of a physical, mental, intellectual or sensorial nature, which, in interaction with various barriers, may obstruct his/her full and effective participation in society on an equal basis with other persons*⁶. This concept broadens the spectrum of people who can be considered under the BPC and recognizes the importance of the interaction of impediments – of corporal nature – with sociocultural barriers that hinder and/or impede the social participation of people with disabilities.

The development of this concept in the INSS to obtain the BPC is performed through the application of specific tools proposed by the aforementioned Ordinance by medical experts and social workers. The interaction between these two professional perspectives is also used in other policies for people with disabilities⁷ and facilitates the identification of factors other than biological, broadening the spectrum of beneficiary subjects and ensuring a more comprehensive view on the recognition of rights.

In the definition proposed by the Brazilian Inclusion Law, the perspective of the concept must be interdisciplinary and multi-professional. In the INSS, regarding the granting of BPC, the medical expert and the social worker are responsible for ensuring integrality in the analysis of the situations of the applicants seeking the benefit. The physician identifies the type of disability and assesses the structures and functions of the applicant's body. The social worker, in turn, is responsible for performing the evaluation of the social aspects of individuals, especially in the environment in which they are inserted. It should be noted that the two analyses are based on the descriptions of the International Classification of Functioning, Disabilities and Health (ICF)³. These strategies aim to ensure compliance with the regulations and the broader view of disability.

It can be said that the BPC assumes an important task in the National Welfare Policy⁸, especially with regard to the inclusion of people with disabilities in the services and equipment of the Unified Welfare System (SUAS) and in the expanded actions to curb social inequality. Moreover, the assurance of income for people with disabilities in situations of extreme social vulnerability facilitates improved quality of life of individuals who have historically experienced situations of oppression, silencing and social isolation^{9,10}.

It is necessary to recognize the prejudice experienced by people with disabilities throughout

history¹¹ to change reality. Traditionally, disability was seen as an eminently individual problem requiring diagnostic and rehabilitation techniques based on biomedical knowledge¹². The authors called this model as “medical model of disability”. Since the 1970s, especially with the claim of people with disabilities in countries such as England (and later Brazil), disability is seen as a collective issue requiring social responses, not just biomedical ones. Thus, it is not only the individual who must be invested with actions of the public power, but also society itself. This movement was labeled “social model of disability”^{13,14}.

Recognizing that disability requires collective action, not just individual ones, places the disabled person in a differentiated care setting. The state will not only intervene through medical diagnosis and rehabilitation techniques in the issue of disability, but also through structural transformations¹⁵. To this end, it is also necessary to ensure the inclusion of families and society in public policies, as well as making environments accessible to all¹⁶.

Reflecting on the inclusion of people with disabilities in services and equipment that ensure social protection, either with income transfer (BPC), that is, with the guarantee of access to public facilities, or by SUAS and the Unified Health System (SUS) – is very important for the transformation of the reality of this population. In recent years, especially between 2015 and 2016, a new concern has emerged with direct consequences on the organization of policies and collective views for people with disabilities: microcephaly in neonates, associated with *in utero* exposure to the Zika virus.

The Zika virus has been described since the 1940s in Uganda and had never been considered a pathogen of great importance because it causes a light health condition with a fast recovery¹⁷. At the same time, the Zika virus had not reached such a susceptible population, which occurred in Latin America, mainly in Brazil. This setting allowed the detection of events not previously described as changes in growth and development related to Zika virus infection in infants born to pregnant women infected by the virus¹⁸.

Injuries described in children with developmental changes related to Zika virus infection are still being described and investigated, but the main ones are classified so far as change in cranial morphology (described as microcephaly), brain anomalies, ocular anomalies and contractures¹⁹.

Genetic and epidemiological investigations have suggested that the virus may have entered

the country during the mass events that occurred between 2013 and 2014²⁰. Its congenital effects were only later perceived and culminated with the declaration of public health emergency by Brazil and by the World Health Organization in February 2016²¹.

Some actions were conducted in Brazil in order to intervene quickly on the Zika issue and its consequences for the affected children and their families. One of the initiatives was the publication of Ordinance MDSA N° 58, dated June 3, 2016, regulating the priority service for families diagnosed with microcephaly in the evaluation of the Continuous Cash Benefit²². This Ordinance recognizes the importance of quick access to BPC in social groups affected by this disease and draws some coordination actions between the health care network, assistance and social security to search for possible beneficiaries and rapid action in the social protection of children and families with microcephaly.

Methods

A descriptive study with aggregated data was performed, observing time and geographic distribution of data on the incidence of microcephaly related to Zika virus in Brazil and the data of BPC grants to children of up to 48 months with diagnosis of microcephaly (ICD Q02), assuming municipalities of the country as primary sampling unit.

The incident cases of microcephaly were obtained from the Epidemiological Report N° 57 of the Ministry of Health, which refers to the Monitoring of cases from 01/01/2015 to 31/12/2016²³. This Epidemiological Report shows information regarding microcephaly and/or CNS changes, provided for in the definitions in force in the Protocol on Surveillance and Response to the Occurrence of Microcephaly and/or Central Nervous System (CNS) - Version 2.1 / 2016²⁴. The Report was prepared by the Ministry of Health with data extracted directly from the Public Health Event Registry (RESP-Microcefalia) and validated by the State Health Secretariats. The microdata used to prepare this Report were provided by the Ministry of Health, upon request based on in the Law on Access to Information. The population estimates used for calculations of BPC and Microcephaly by Federative Unit (UF) rates were obtained from the DATASUS website, containing the projection of children in the 0-4 years age group per UF performed by the IBGE.

The 2009-2016 historical series for BPC grants to children of up to 48 months with diagnosis of microcephaly (ICD Q02) was elaborated from microdata provided by the National Institute of Social Security and the Ministry of Social Development, upon request based on the Law on Access to Information. ICD Q02 classifies the clinical condition of microcephaly regardless of its etiology. Data requested and obtained did not allow the identification of individuals, since they only contained the information of the age group and the municipality of residence of the beneficiary. Proportions, means and standard deviation were calculated, where appropriate.

The research analyzed databases without possibility of individual identification, waiving analysis by the Ethics Committee.

Results

The Ministry of Health reported that from January 1, 2015 to December 31, 2016, 10,867 cases of microcephaly were reported according to the parameters of the Surveillance Protocol, of which 3,183 cases (29.3%) were still under investigation. Of the 7,684 cases that were investigated and classified, 2,366 were confirmed, 49 classified as probable and 5,269 discarded. There are still 3,183 cases under investigation. Figure 1 shows the distribution of the 751 municipalities of residence of the 2,366 confirmed cases of microcephaly and/or central nervous system changes associated with the Zika virus²³.

The trend of the number of BPCs granted between 2009 and 2016 for children younger than 48 months at the time of granting the benefit, diagnosed with ICD Q02 (microcephaly) is shown in Figure 2. In the period 2009-2014, a relatively stable baseline is observed, with a mean and standard deviation of 200 ± 31 annual benefits granted in this age group. By 2015, the number of benefits was below the historical average, probably due to an INSS strike that lasted almost six months²⁵. In 2016, the number of grants for this disability in this age group reached 1,603 benefits, increasing eightfold the average of grants.

The distribution by region, Federative Unit (UF) and by capital of residence of beneficiaries of up to 48 months of age with BPC granted in 2016 is shown in Table 1. BPCs were granted in 731 municipalities of all 27 Federative Units. The analysis shows that the Northeast accounted for 73.1% of PCBs granted, which was ratified by the highest grant rates, consistent with the national

framework of the Zika virus epidemic. The UF with the highest absolute number of benefits granted was Pernambuco ($n = 281$ or 17.5% of the total), followed closely by Bahia, with 263 (16.4% of the total). Among the capitals only Vitória, Goiânia and Campo Grande were not granted BPCs. Salvador, with 79 BPCs, and Rio de Janeiro, with 40 BPCs are the capitals with the highest number of BPCs granted.

As described in the methodology, the INSS expert physician classifies the clinical condition of microcephaly as ICD Q02, regardless of its etiology. Even considering this limitation, Table 1 shows the number of notified and confirmed cases of microcephaly and/or Central Nervous System changes associated with the Zika virus per Federative Unit, for comparative and programmatic purposes.

The “coverage” by UF was not calculated, due to possible large variations caused by the analysis of small figures. Thus, it was decided to calculate the national and regional parameters, resulting in: Brazil 67.8%; North 94.6%; Northeast 64.9%; Southeast 84.6%, South 181.5% and Midwest 30.3%. A coverage below 65% is observed in the Northeast, the most affected by microcephaly in Brazil. In addition, access to BPC of children diagnosed with microcephaly in the Midwest is low.

The analysis of coverage data should take into account that, in 2016, similar to previous years, about 200 cases of microcephaly from various causes were granted BPCs throughout the national territory. Therefore, the real access to the benefit for Zika virus-associated microcephaly cases in the Northeast should be lower than the 65% calculated here.

The spatial distribution by municipality of residence of beneficiaries who were granted BPCs in 2016 is illustrated in Figure 3. The map indicates that the grant of PCBs for children with microcephaly is concentrated in the Brazilian northeast and in large cities, especially in the metropolitan regions. However, it is also present in different rural state municipalities.

The map also indicates a concentration of benefits granted to children with microcephaly in Pernambuco not only in the capital and in the metropolitan region, but also in most of the state. In the same way, we highlight Maranhão and Paraíba: the rural area of the state has a significant mean concentration of cases. We can also perceive that the granting of at least one benefit is spread across several cities. This is visible in several Brazilian states (and not only in the North-

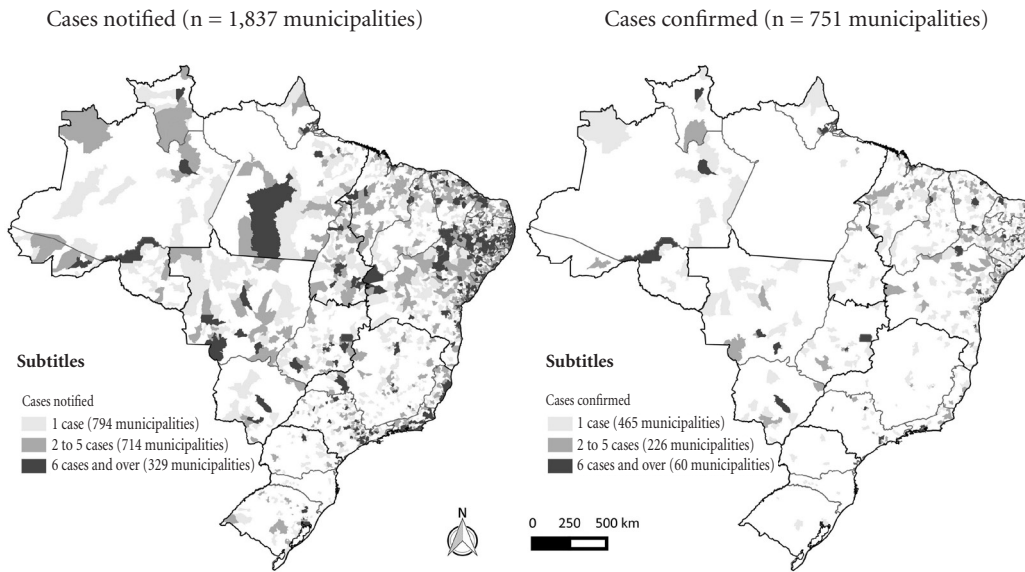


Figure 1. Spatial distribution of reported and confirmed cases of microcephaly and/or Central Nervous System change associated with Zika virus. Brazil, 01/01/2015 to 31/12/2016.

Source: Epidemiological Report No 57 - Epidemiological Week (SE) 52/2016 (25th to 31th, december 2016). Monitoring of microcephaly cases in Brazil (23). Image from Department of Health Surveillance / MS

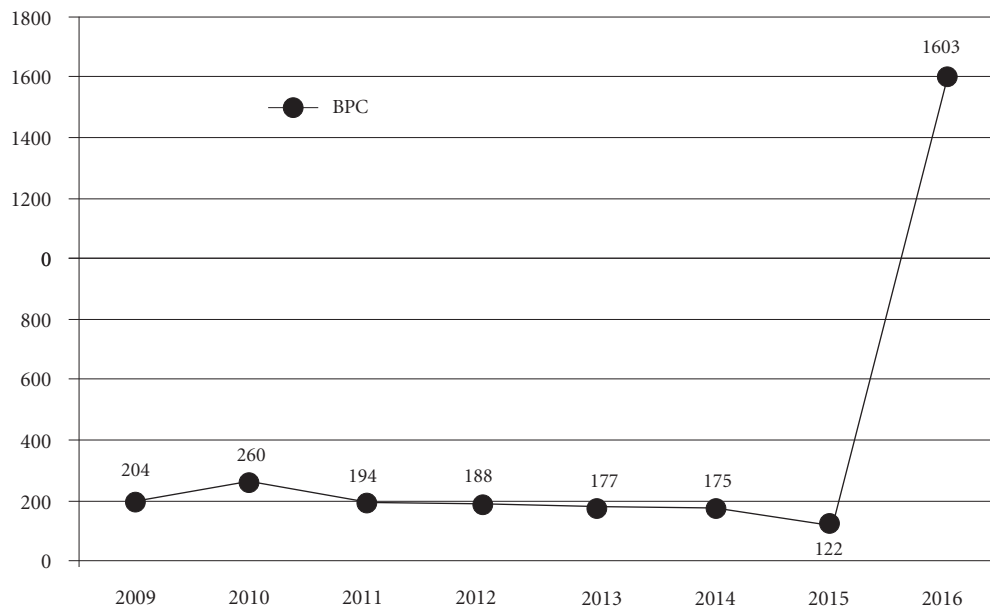


Figure 2. Historical series of the number of Continuing Cash Benefits granted to children up to 48 months of age with diagnosis of microcephaly. Brazil, 2009-2016.

Source: Own elaboration from microdata provided by the National Institute of Social Security / Ministry of Social Development

Table 1. Distribution of Continuous Cash Benefits granted to children up to 48 months with diagnosis of microcephaly, number of confirmed microcephaly cases and respective rates for population up to 48 months, by Region and Federative Unit in which they reside. Brazil, 2015-2016.

UF/ Region	N° BPC granted UF/ Region 2016 ^a	Proportion of total BPC Brazil (%) 2016 ^a	Capital of the Federative Unit	N° of BPC granted in the Capital 2016 ^a	Proportion of total BPC of the UF (%) 2016 ^a	N° cases of microcephaly confirmed			Rate ^c of BPC Granted 2016 ^a	Rate ^c of cases of microcephaly 2016 ^b
						2015-2016 ^b	2015 ^b	2016 ^b		
Acre	7	0.4	Rio Branco	5	71.4	2	0	2	8.23	2.35
Amapá	5	0.3	Macapá	3	60.0	11	1	10	4.01	6.52
Amazonas	16	1.0	Manaus	7	43.8	26	0	26	6.43	12.86
Pará	36	2.2	Belém	3	8.3	8	2	6	4.72	0.79
Rondônia	6	0.4	Porto Velho	1	16.7	12	0	12	4.32	8.65
Roraima	7	0.4	Boa Vista	3	42.9	13	0	13	13.95	25.91
Tocantins	10	0.6	Palmas	3	30.0	20	3	17	7.73	13.15
North	87					92	6	86	5.30	5.24
Alagoas	58	3.6	Maceió	15	25.9	90	19	71	20.45	25.03
Bahia	263	16.4	Salvador	79	30.0	433	164	269	23.19	23.72
Ceará	117	7.3	Fortaleza	30	25.6	152	55	97	17.19	14.25
Maranhão	134	8.4	São Luiz	27	20.1	160	42	118	20.27	17.85
Paraíba	104	6.5	J. Pessoa	29	27.9	191	96	95	34.04	31.10
Pernambuco	281	17.5	Recife	35	12.5	408	267	141	39.65	19.90
Piauí	49	3.1	Teresina	18	36.7	100	23	77	20.03	31.47
RG Norte	70	4.4	Natal	13	18.6	142	91	51	27.34	19.92
Sergipe	95	5.9	Aracaju	19	20.0	128	84.0	44	54.48	25.24
Northeast	1.171					1,804	841	963	26.32	21.65
Espírito Santo	12	0.7	Vitoria	0	0.0	36	3,0	33	4.48	12.32
Minas Gerais	62	3.9	B.Horizonte	5	8.1	19	0	19	4.58	1.40
Rio Janeiro	101	6.3	R.Janeiro	40	39.6	179	45	134	9.93	13.17
São Paulo	77	4.8	São Paulo	11	14.3	64	7	57	2.71	2.01
Southeast	252					298	55.0	243	4.60	4.43
Paraná	14	0.9	Curitiba	3	21.4	3	0	3	1.90	0.41
RG Sul	20	1.2	Porto Alegre	2	10.0	18	1	17	2.98	2.53
Santa Catarina	15	0.9	Florianópolis	2	13.3	6	0	6	3.42	1.37
South	49					27	1	26	2.65	1.41
Distrito Federal	5	0.3	Brasília	5	100.0	13	2	11	2.38	5.24
Goiás	7	0.4	Goiânia	0	0.0	47	6	41	1.53	8.97
Mato Grosso	27	1.7	Cuiabá	6	22.2	57	11	46	10.56	17.99
Mato Grosso Sul	5	0.3	Cpo Grande	0	0.0	28	1	27	2.44	13.20
Midwest	44					145	20	125	3.90	11.09
Total	1.603	100.0		364	22,7	2,366	923	1,443	11.02	9.92

Source: Own elaboration based on (a) microdata provided by the National Institute of Social Security / Ministry of Social Development (b) microdata provided by the Ministry of Health and Epidemiological Report No. 57 / MS (23) (c) Per 100,000 inhabitants (children 0-48 months).

east), including in the South and Midwest. These cases probably represent microcephaly from various causes that annually request and obtain BPC in Brazil (mean of 200 per year).

Discussion

The BPC is a State policy that ensures a minimum income for vulnerable subjects – the elderly and

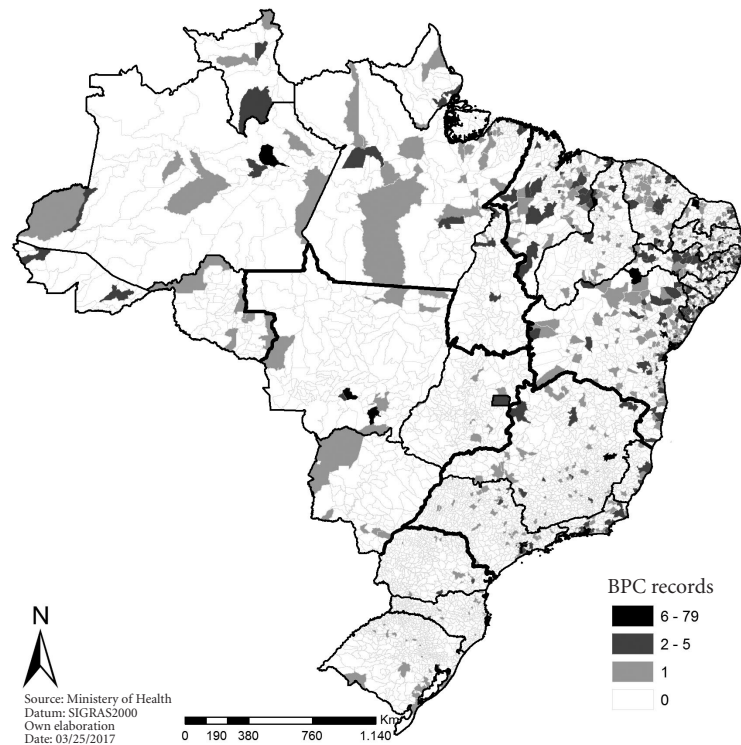


Figure 3. Spatial distribution of Continuing Cash Benefits granted in 731 municipalities for children up to 48 months of age with microcephaly, Brazil, 2016.

Source: Own elaboration from microdata provided by the National Institute of Social Security / Ministry of Social Development.

people with disabilities. In the organization of the Unified Welfare System (SUAS), BPC beneficiaries must be accompanied by basic social protection equipment, especially Social Welfare Reference Centers (CRAS). CRAS can assist in monitoring BPC beneficiaries to avoid breaking social ties and increasing their social participation⁸.

Ensuring access of children with microcephaly associated with the Zika virus and their families to basic social protection equipment is fundamental to promote the social insertion of the extended network that may assist in the care of children with microcephaly. In addition, basic social protection will provide information necessary for the active search and monitoring of these families in other public policies²⁶.

Continuous Cash Benefit (BPC) beneficiaries are people with great economic vulnerability. The income required to apply for the benefit indicates that the family needs different actions from the State. Organizing a social protection network,

with the follow-up of basic social protection is essential to ensure that these individuals envision leaving the lower strata of poverty. Thus, actions that ensure access to different public policies are quite important, because disability will bring a lifelong social cost to the subject and his family, imposing on the State the need to organize a network of services in a comprehensive, equitable way with an effective longitudinality.

Several studies have demonstrated the importance of BPC in transforming the quality of life of its beneficiaries and their families²⁷⁻³⁰. The constitutional guarantee of a minimum income enables those involved to broaden social performance, as well as to provide better quality and, somehow, to indicate and/or build an easy access of these subjects to public policies. The State must ensure the expanded access of this population to BPC and other social policies.

This work points to the importance of BPC for the reorganization of the routine of families

in this condition, especially those in which children were born with microcephaly, or even other severe incapacitating injuries related to Zika virus infection during pregnancy. Since they are children, and because of the particularity of the consequences of the syndrome in the functionality of individuals, it will be necessary to build a set of intersectoral actions to ensure their social inclusion and that of their families. The importance of intersectoral actions is well known, especially for people with disabilities³¹. In the case of children with microcephaly, in addition to social welfare (through CRAS and BPC), it is necessary to build a health and education network to accommodate diversity and enable real inclusion in a human rights perspective.

After all, family characteristics of children with microcephaly of the studies described so far are due to severe socioeconomic fragility, such as the mothers of microcephalic children of Sergipe who had an average income of R\$ 266.00 (interquartile: R 6.66-2,666.00)³². In Pernambuco, the average per capita household income of children born with microcephaly due to Zika virus was R\$ 400.00 (interquartile: R\$ 215.50-533.00)³³. Thus, as already mentioned by Brunoni *et al.*³⁴, the health care system has a great challenge ahead, as it is still trying to understand the meaning of the real spectrum of the teratogenic potential of this virus.

In addition, Brazil and other Latin American countries also have weaknesses in family planning policies³⁵, even if multilateral organizations seek to guide post-conception palliative measures³⁶. Thus, the social support system of the Brazilian State may be the great turning point for better quality of life of newborns with microcephaly and their family, reaffirming the constitutional commitment of the State to social welfare.

Studies carried out in the context of microcephaly in the Brazilian northeast show, however, families' difficult access to PCBs³⁷. On the one hand, there are red tape barriers that hinder ac-

cess, among them the working hours of agencies that enable women (mostly mothers) caregivers to seek their rights. On the other hand, the income required for the granting of the Continuous Cash Benefit determines that only people living in situations of extreme poverty can have access to it – which exempts the federal government from assisting poor families that are not in extreme poverty.

Nonetheless, information on BPC grants to children diagnosed with microcephaly indicates a significant increase in 2016. Most of the benefits granted were in the Northeast.

The expressive increase of children with microcephaly in the Northeast has important consequences for public policies. Children with microcephaly and their families should have access to policies for people with disabilities that ensure inclusion in all walks of social life. It is necessary to reflect on the best ways to expand health, social welfare and education networks in Brazilian municipalities, as well as strengthen links between families and children with microcephaly. The social safety network is very important for people with disabilities. However, it is necessary to reflect on the need to strengthen care policies beyond the subject diagnosed with disability. Families, in general, and mothers, in particular, play a key role in ensuring the quality of life of children with disabilities. Thus, it is strategic that affirmative actions that ensure access to public policies consider the whole social environment and the family core in which the individual is inserted.

We must stress the importance of establishing the SUAS-SUS-INSS reference system, proposed by the MDSA Ordinance N° 58²² so that more children with microcephaly and other sequelae that can cause loss of functionalities, not only due to the Zika virus have access to BPC, vis-à-vis other congenital infections that are on the rise in the country, mainly affecting unequally disadvantaged populations.

Collaborations

EL Pereira and LMP Santos worked on the design and writing of the paper; JC Bezerra, JL Brant, WN Araújo and LMP Santos were responsible for obtaining and analyzing data. All the authors collaborated in the critical review and analysis of the literature, in the final writing and in the approval of the version to be published.

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