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Participation of children with Congenital Zika Virus Syndrome: intersections between the bioecological model and human functionality

A participação de crianças com a Síndrome Congênita do Zika Vírus: interseções entre o modelo bioecológico e a funcionalidade humana*

La participación de niños con el Síndrome Congénito del Virus del Zika: intersecciones entre el modelo bioecológico y la funcionalidad humana

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Abstract: This article presents results of the participation and functionality of children with multiple disabilities due to Congenital Zika Virus Syndrome in activities performed at home. The qualitative research was carried out in Baixada Fluminense, Rio de Janeiro, Brazil. To collect information, we used the instrument Participation and Environment - Children and Youth (PEM-CY). The data were analyzed based on the references of the bioecological and systemic theory of human development by Uri Bronfenbrenner, in dialogue with the perspective of human functionality of the World Health Organization. The results

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showed that mothers are not only the main person responsible for the daily care of children at home, but also for developing different strategies to expand the participation and functionality of the child in daily activities, being, therefore, protagonists of the social and educational inclusion. They also indicated the need for intersectoral programs and actions to favor the development of these children and improve the quality of life and their well-being.

Keywords: Participation. Human functionality. Bioecological theory. Multiple disability. Congenital Zika Virus Syndrome. Special Education.

Resumo: Este artigo apresenta resultados da participação e da funcionalidade de crianças com deficiência múltipla em decorrência da Síndrome Congênita do Zika Vírus em atividades realizadas em ambiente domiciliar. A pesquisa qualitativa foi realizada na Baixada Fluminense, Rio de Janeiro, Brasil. Para colher informações, utilizamos o instrumento *Participation and Environment – Children and Youth* (PEM-CY). Os dados foram analisados a partir dos referenciais da teoria bioecológica e sistêmica do desenvolvimento humano de Uri Bronfenbrenner, em diálogo com a perspectiva da funcionalidade humana da Organização Mundial de Saúde. Os resultados evidenciaram que as mães não são apenas as principais responsáveis pelos cuidados diários das crianças em casa, mas também elaboram diferentes estratégias para ampliar a participação e a funcionalidade do(a) filho(a) nas atividades diárias, sendo, por isso, protagonistas da inclusão social e educacional. Indicaram, também, a necessidade de programas e ações intersetoriais para favorecer o desenvolvimento dessas crianças e melhorar a qualidade de vida e seu bem-estar.

Palavras-chave: Participação. Funcionalidade humana. Teoria bioecológica. Deficiência múltipla. Síndrome Congênita do Zika Vírus. Educação Especial.

Resumen: Este artículo presenta resultados de la participación y funcionalidad de niños con múltiples discapacidades por Síndrome Congénito del Virus Zika en actividades realizadas en el ambiente domiciliar. La investigación cualitativa fue realizada en Baixada Fluminense, Río de Janeiro. Para recolectar informaciones utilizamos el instrumento *Participation and Environment – Children and Youth* (PEM-CY). Los datos fueron analizados a partir de los referenciales de la teoría bioecológica y sistémica del desarrollo humano de Uri Bronfenbrenner, en diálogo con la perspectiva de la funcionalidad humana de la Organización Mundial de la Salud. Los resultados mostraron que las madres no sólo son las principales responsables de los cuidados diarios de los niños en el hogar, sino que también elaboran diferentes estrategias para ampliar la participación y la funcionalidad del hijo(a) en las actividades diarias, siendo, por tanto, protagonistas de la inclusión social y educativa. Indicaron también la necesidad de programas y acciones intersectoriales para favorecer el desarrollo de estos niños y mejorar la calidad de vida y su bienestar.

Palabras clave: Participación. Funcionalidad humana. Teoría bioecológica. Discapacidad múltiple. Síndrome congénito del virus del Zika. Educación Especial.

Introduction

> *We can only become a presence in the world populated by others*
> *who are not like us, a world of plurality and difference.*
> (Biesta, 2017, p. 27).

Multiple disability resulting from Zika virus infection is not characterized only by a set of two or more disabilities - physical, sensory, mental, among others - associated, as is commonly defined in national legislation and in the scientific literature (Early childhood education: knowledge and practices of inclusion [*Educação infantil: saberes e práticas da inclusão: dificuldades acentuadas de aprendizagem: deficiência múltipla*], 2006; Rocha, 2014, 2018). Children who were born with multiple disabilities as a result of the Congenital Zika Virus Syndrome (CZVS) also have, for the most part, complex chronic health problems. Epidemiological discussions on the profile of health conditions with the increase in chronic conditions, including those with infectious transmissibility, have been held since the 1990s (Moreira & Goldani, 2010). The definition of Chronic Health Condition (CHC) encompasses both chronic and infectious diseases and the most varied disabilities, due to common characteristics such as: temporality and continuity of care, symptom control and longitudinal care, intervention and support/assistance, as defined by the World Health Organization (WHO, 2003).

The manifestation of a CHC in a period in which the physiological neuropsychomotor improvement is still in development, as in childhood, has a strong impact on the life of the individual and the family members (Cohen et al., 2011; Moreira et al., 2017). Often, the life of the child and those of his/her family members come to be governed by the CHC, affecting all the interaction of this child at school and in society, reflecting on the development of functionality and participation in activities of daily and social life (Sá et al., 2015). In the case of our investigations with people with severe multiple disabilities, we have carried out analysis and interventions based on the intersectoral debate that involves discussions and advances in the area of CHC, as is the case of children with CZVS (Sá et al., 2019; Pletsch & Mendes, 2020; Pletsch et al., 2020).

When we refer to the term functionality in the case of children with multiple disabilities due to CZVS, we highlight what the child can or cannot do in his/her daily life, considering the functions of the organs and systems, body structure, activity limitations and restrictions on educational and social participation in the environment in which these individuals live (WHO, 2003). In other words, we use here the term "functionality" based on the concept introduced by the International Classification of Functionality, Disability and Health - ICF (WHO, 2007), which understands it as a dynamic interaction between health problems and contextual factors, both personal and environmental. We understand, therefore, disability not as an attribute of the person, but as a result of social interaction, since non-accessible environments amplify the disability by imposing barriers for the participation and inclusion of these people. This perspective takes as a reference the social model of disability that comprehends it as a social phenomenon and not as a direct and unique influence of bodily injuries (Diniz et al., 2009).

Based on this discussion, this paper presents the results of a pilot study conducted with two children with multiple disabilities as a result of CZVS to analyze the participation and family support given to them in activities carried out at home. After the global pandemic caused by the new "coronavirus" (SARS-CoV-2), declared by the WHO on March 11, 2020, we also analyzed the participation and support offered to these children in school.

Our assumption is that participation at home, at school or in the community positively affects the functionality and, consequently, the development of these children, as long as the appropriate support and assistance is offered. Likewise, we understand that, from the perspective of human functionality, participation and contextual aspects, whether environmental or personal are important elements to be analyzed when considering the subject's participation in social and school life. The limitations in the performance of daily activities imposed by the disability, associated with restrictions on participation, will certainly affect the child's performance in the family, school or community. Our hypothesis is that analyzing and knowing the child's participation in activities at home and at school are essential to propose interventions in a collaborative and intersectoral way, in order to favor their functionality, educational and social participation and contribute to the improvement of their quality of life and well-being.

Theoretical premises and methodological aspects

The qualitative research developed collaboratively with the participants of the *Fórum Permanente de Educação Especial na Perspectiva Inclusiva da Baixada e Sul Fluminense*[1] (Permanent Forum of Special Education in the Inclusive Perspective of the *Baixada* and *Sul Fluminense*[2]) integrates one of the stages of the multidisciplinary project that articulates 55 researchers from different institutions (Federal Rural University of Rio de Janeiro - UFRRJ; University of the State of Rio de Janeiro - UERJ; Pontifical Catholic University of Rio de Janeiro - PUC-Rio; State University of Santa Catarina - UDESC; Oswaldo Cruz Foundation - Fiocruz; National School of Public Health - ENSP; and Fernandes Figueira Institute - IFF) to develop studies and intersectoral actions between education, health and social assistance in promoting schooling and the development of children with CZVS in Baixada and Sul Fluminense (Pletsch, 2018, 2019). We inform that the project was approved by the Ethics Committee of the Federal Rural University of Rio de Janeiro (UFRRJ), Protocol no. 135/2021 (Process no. 23083.031153/2019-40).

To collect the information, we conducted interviews with the mothers of two children with multiple disabilities as a result of CZVS, enrolled in Early Childhood Education classes in schools of two municipalities in Baixada Fluminense, and applied the instrument Participation and Environment - Children and Youth (PEM-CY)[3], developed at Boston University, to assess participation in different contexts of children and young people up to 17 years of age: at home, at school and in the community. For the interviews, which were carried out virtually using the zoom platform, we used a semi-structured questionnaire with socioeconomic and contextual issues. To collect the information with the PEM-CY, a home visit was carried out with two researchers, who followed the epidemiological safety protocols for the prevention of COVID-19. It is important to mention that the PEM-CY was validated for the Brazilian reality (Monteiro, 2017; Galvão et al., 2018), but it has not yet been applied to children with multiple disabilities. Table 1 below summarizes the information about the participants.

Table 1 - Description of the participants[4]

Family Participant	Son/Daughter	Description
Camélia - mother, 23 years old	Ana Flor – 4 years old	She was born with CZVS and has multiple disabilities, classified by GMFCS LEVEL V[5], uses an adapted manual wheelchair; uses adaptation devices: orthosis for arms and legs (AFO), is non verbal, has no mobility in the hands and arms.
Clara - mother, 36 years old	João – 4 years old	He was born with CZVS and has multiple disabilities, classified by GMFCS LEVEL V, uses an adapted manual wheelchair, is non verbal , has limited mobility in his hands and arms.

Source: Elaborated by the authors.

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[1] Created in 2015 within the scope of the Observatory of Special Education and Educational Inclusion (ObEE), the Forum currently integrates Special Education managers from teaching networks in the Municipalities of Baixada and Sul Fluminense, as well as researchers from UFRRJ, Nova Iguaçu Campus, and the UERJ, Duque de Caxias Campus.

[2] Geographic region of the state of Rio de Janeiro. The cities that make up the region are: Belford Roxo, Duque de Caxias, Guapimirim, Japeri, Queimados, Magé, Mesquita, Nilópolis, Nova Iguaçu and São João de Meriti.

[3] License for use number 13334 - PEM-CY.

[4] For the pilot evaluation, we selected two children with CZVS who were about to complete 5 years of age. The objective was to assess the feasibility of using the PEM-CY instrument in the research project due to the complexity of the cases.

[5] The Gross Motor Function Classification System (GMFCS) is a five-level clinical classification system that describes the gross motor function of people with cerebral palsy. It is based on the movement started voluntarily, with an emphasis on sitting, transfers and mobility. The distinctions are based on functional limitations, the need for manual devices for mobility (such as walkers, crutches or walking sticks) or mobility on wheels, and to a lesser extent, on the quality of movement (Palisano et al., 2007, p. 1).

PEM-CY consists of a set of questions about the participation of children or young people in different activities at home, at school and in the community. In this paper, we present only the results on children's participation in activities at home, in order to assess whether they need a lot of support to perform them, little support or no support due to their multiple disabilities. We also analyzed contextual aspects such as housing conditions, the Human Development Index (HDI) of the region, the social and economic conditions of the family, as well as the existence of a support network for mothers.

For the qualitative analysis of the data, we used the references of the bioecological and systemic theory of human development by Uri Bronfenbrenner (2012), currently called the "bioecological model". This perspective emphasizes that the interaction between several factors (child, family and social/community environment), with a focus on quality and in the context of relationships with these environments, favors child development. We believe that this perspective is linked to the human functionality model, previously discussed.

Talking about human development implies considering that it occurs contextually based on the dynamic and interrelated components of the model proposed by Bronfenbrenner, namely: a) **Person**, understood from his/her biopsychological characteristics and those constructed in the interaction with the environment; b) **Process**, seen as responsible for development and occurs through reciprocal and increasingly complex interaction between one human being and other people, objects and symbols in an immediate environment, which Bronfenbrenner called proximal processes; and c) **Context**, which refers to the person's life contexts and is analyzed through the interaction of four environmental levels systematized in Table 2 below. To the author, these systems are organized as a fitting of concentric structures, composing what he calls an ecological-environment.

Table 2 - Levels of the Bronfenbrenner bioecological model

Level	Explanation given by the bioecological model
Microsystem	It is characterized by the environment in which the person lives direct personal experiences: family, school, daycare.
Mesosystem	It occurs when there are interrelations and reciprocal influences between two or more environments in which the person actively participates.
Exosystem	It includes elements of the system that do not involve the person as an active participant, but in which events occur that affect what happens in one of the microsystems..
Macrosystem	It comprises the global pattern of ideologies, beliefs, values, religions, forms of government, cultures and subcultures present in people's daily lives.

Source: Elaborated by the authors based on Bronfenbrenner (2012).

To Bronfenbrenner (1992, 1996, 2012), child development occurs as the child is actively involved with the physical and social environment, as well as he/she understands and interprets it. The relationships between an active individual and the context in which he/she performs it and the ecological multilevel are the strength of human development. According to this perspective, the individual exists at a more intimate level, formed by a set of intertwined structures that together make up the ecological context (Martins & Szymanski, 2004; Bronfenbrenner, 2012; Christmann, 2019). This model prioritizes the study of human development in a real-life context, in order to glimpse the entire ecological system in which it occurs as well as the interactions established therein.

When reflecting on the development of a child with a disability in the light of the bioecological model, we understand the importance of an enriched environment, as well as the dimensions of the child's relationship with the closest social media, such as the family and the culture. Portes et al. (2013) highlight that the potential for risk or protection from factors is directly related to the environmental and developmental conditions in which the child is integrated, highlighting this way that the potentialities are directly geared to the environmental or contextual conditions to which they are inserted.

In a study on Early Childhood Education intervention programs, according to the bioecological perspective, Cappelaro-Kobren et al. (2020) point out that this educational level represents a microsystem of great influence on human development and can create opportunities for identification and effective responses to development problems. The authors also state that the intervention aimed at children from 0 to 6 years old aims to respond to the needs presented by children with developmental changes or who are at risk of presenting them.

Sá et al. (2019) report the experience of building an intersectoral project, centered on the relationship between health and education, articulating families with children living with CVZS, and continuing education actions for education professionals who worked with them. The focus was precisely to contribute to the school inclusion of children with multiple disabilities born with CZVS. The research results pointed out that this approach proved to be essential for the transition of children with CZVS, who tend to occupy hospitals and clinics, to the school environment, which is par excellence “a child’s place”. In this sense, investing in the relationship between family and school to promote the participation and well-being of children with multiple disabilities, in an integrated and collaborative way, through educational programs and actions, favors participation and the development of their functionalities in plural and diverse contexts as the inclusive school is (National Special Education Policy from the Perspective of Inclusive Education [*Política Nacional de Educação Especial na perspectiva da Educação Inclusiva*], 2008; Law no. 13.146, of July 6, 2015).

In the field of disability studies, the ICF represents a milestone for the discussion of participation by relating it to the social perspective of functionality and conditioning it to contextual factors. According to the ICF, participation represents the interaction of the child’s or adolescent’s abilities with the physical and social environment in which they are inserted (Santos et al., 2016). In most children with disabilities, especially those with more severe multiple disabilities, functional skills are elements that can modify their participation, as stated earlier (King et al., 2003; Anaby et al., 2012, 2013).

The concept of participation is complex and often polysemic. We will assume here the idea that participation is under the influence of both the personal factors of the child and his/her family, but also of environmental factors. We understand, therefore, that participation is a multidimensional construction, directly affected by factors related to the characteristics of the child, his/her family and environment (Bronfenbrenner & Morris, 2006). Given the dependence of the developing child, here specifically on children with multiple disabilities due to CZVS, the physical and social elements of the environment have a significant impact on its functionality by conceiving it in the dynamic interaction between his/her disability and health conditions and contextual factors, including personal and environmental factors. However, we cannot forget that individuals have an active role in the face of the social situation in which they are inserted, since their attitudes also contribute to (re)define a given social situation. Taking these premises as a background, we present, next, the discussion of the research results.

Child participation, care and functionality from the perspective of the mother/family

Many of these children, as is the case with the participants in this research, are non verbal and demand the use of alternative communication to communicate, have autonomy and participation in their choices in everyday life (Rocha, 2018). For example, introducing the idea of choice through yes and no is decisive to expand the possibilities of these children, whether in the choice of what they prefer to eat, dress, or, mainly, for the development of alternative forms of communication by boards or digital resources on tablets. Alternative communication (AC) - which integrates the assistive technology (AT) area[6] - involves gestures and facial expressions to various graphic forms, as a way of communicating with people who are unable to use verbal language. Still, it considers the purposes of promoting and supplementing speech and that of guaranteeing a new alternative, in case there is no possibility of developing it (Rocha & Pletsch, 2018). Regarding the forms of communication with their children, the mothers participating in this research reported that they understand them by the ways they look, smile and even cry.

João's mother has already introduced the idea of choice, always giving more than one option to her son. She reported that this strategy has been very important to better understand the child's desires with regard to what he likes and dislikes. The son's achievements, even if small, are cause for celebration: "*I learned to value minimal things, anything he does, I cheer, I cheer for small achievements*" (Clara, João's mother, in an interview, January 18, 2021). This strategy is fundamental for new actions and more systematic programs of alternative communication to be introduced for João. In addition, communication favors the structuring of language and thought through the appropriation of the symbolic system, a central aspect for learning and, consequently, for development (Rocha & Pletsch, 2018).

In this regard, the mothers' report about the importance of the child's entry into school caught our attention, despite not being the object of this stage of the research. Mothers choose to enroll their children in regular schools, the so-called inclusive schools, because they believe that there they would develop more when interacting with other children. One of the hypotheses of our investigation, to be confirmed after the end of the pandemic, in the research phase to be carried out at school, is that the enrollment of these children in regular teaching classes, with the appropriate support, favors their well-being and, therefore, qualifies their schooling and health conditions. Santos et al. (2016, p. 3117) had already found that participation in the school environment is an important point for health promotion, development, growth and sociability.

It is worth mentioning that we have appropriated the concept of well-being of the Pan American Health Organization and the World Health Organization (PAHO/WHO), which understand it as "Health is a state of **complete** physical, mental and social **well-being** and not merely the absence of disease or infirmity." (PAHO; WHO, 2016, emphasis added). We can consider, in a first perspective, that the meaning of well-being can be the subjective notion of feeling good, having no complaints, not having somatic or psychological suffering, nor being aware of any injury or impairment of personal or social performance. However, well-being also means a condition of satisfying needs (conscious or unconscious, natural or psychosocial). In human beings, it implies the satisfaction of biological needs - physical well-being; psychological needs - mental well-being; and social needs - social well-being (Galinha & Ribeiro, 2005). Let's take a look at the mothers' reports on inclusive school:

> Although she is "special", she is a child who has a unique personality. She is a child who is very difficult to like another child, but here in my house I have three nephews who got along with her very well and she got along with them very well. Literally, very well, she interacted with them and they interacted with her. So, by coexisting with the boys, I realized that they used to play, and she also wanted to play with them. They played, they spoke loudly and she babbled or, else, she screamed. That made me want to put her in a regular school with other children. Not only because she would be with other children,

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[6] According to Law no. 13.146, of July 6, 2015, which institutes the Brazilian Law for the Inclusion of Persons with Disabilities, Assistive Technology equipment or technical assistance are products, equipment, devices, resources, methodologies, strategies, practices and services that aim to promote functionality, related to the activity and participation of people with disabilities or reduced mobility, aiming at their autonomy, independence, quality of life and social inclusion.

> but her schoolwork would also help her in some way. Her routine at school, seeing other children, the teacher talking and her recognizing what the teacher is saying... Even at home, when the teacher sent videos, she recognized her voice, the homework of today, if you would repeat tomorrow what was written she would understand what it was, she knew what it was because she would smile. She pays a lot of attention. So, I believe these were her improvements after going to inclusive school. I believe that it was coexisting with other students, the tasks, her adaptation at school. (Camélia, Ana Flor's mother, in an interview, January 11, 2021).

> I live in front of a school and every day before the pandemic he was in front of my house right when the children left the school. My son was happy and smiling watching the children playing and leaving school. I noticed that he wanted to interact and that was what made me choose an inclusive school. In addition, I defend inclusion because I believe that children who live with my child will be less prejudiced towards other people with disabilities. (Clara, João's mother, in an interview, January 18, 2021).

As we can infer, the entrance into the school of these children from the mothers' perspective has been important and has positively affected their children's participation and functional development. In this sense, we have argued that proposing intersectoral actions between education, health and social assistance, taking as a reference the social model of disability and human functionality for these children, requires rethinking the social function of the school as an institution that, by embracing diversity, expands student development possibilities (Dainez & Smolka, 2019; Pletsch et al., 2020; Pletsch & Souza, in press). It also points to the importance of collaborative work between different professionals with the families of these children to share information, knowledge beyond the disciplinary boundaries of each area (Sá et al., 2019). Developing actions expanding the idea of "*family-centered care employed in health*" to other areas, such as education and social assistance, seems to be a necessary way to guarantee not only the social rights of children with multiple disabilities as a result of CZVS, but also to implement intervention programs to promote their integral development. We believe that the school, due to its central role in the lives of children and their families, is the space par excellence for the orchestration of intersectoral actions.

Another piece of research refers to the care of the child's daily life and the organization of his/her routine, whether educational or weekly therapy, which falls under the responsibility of the mothers, as already indicated in previous studies (Pletsch & Mendes, 2020; Fleischer & Lima, 2020; Lima & Souza, 2021). Ana Flor's mother - resident in Belford Roxo, which is in the 73rd position of the State of Rio de Janeiro in the HDI, with 0.684, - said that when she needs help, she can count on her parents and brothers, but that the responsibility of care taking is hers. She told us that "*when you have a special child, life changes a lot, I had to give up my dreams, I gave up practically everything to take care of her*" (Camélia, Ana Flor's mother, in an interview, on January 11, 2021). João's mother - resident of São João de Meriti with HDI 0.719, in 34th position in the State of Rio de Janeiro - reported that, despite having the support of her husband, daughter and parents, most of the care is under her responsibility. Both mothers had to stop working after the children were born and currently have the benefit of continued provision and, in 2020, they also received emergency assistance from the Federal Government offered during the COVID-19 pandemic.

In health, the concept of care has been widely discussed in the last 20 years. Literature has been extended, and some definitions of what consists of care and care modalities have been improved and expanded. The term "care" means solicitude, concern for others, being attentive to their needs, which are meanings present in their definition (Agostini, 2019). Hirata (2012, p. 286) defines care as the type of social relationship that takes place, having as an object another person. Gilligan (1993) proposes the logic of care ethics centered on interpersonal relationships and which values responsibility, responsiveness that includes affection, attention to the other supported by an understanding of the human world (Kuhnen, 2010; Hirata, 2012; Agostini, 2019). However, we understand, according to Fietz and Mello (2018), that the multiplicity of discourses, in different areas of knowledge, becomes precisely the power to think about disability issues based on care relationships. The authors emphasize that care is a key category to open new dialogues in the field of knowledge and practices.

We understand, therefore, that the discussion of the concept of care, related to the field of education, has great relevance, when we speak of inclusive education, for example, of children with CZVS, who demand greater support in the classroom in order to participate effectively in the teaching and learning processes. It is what Kittay (2012) conceives as a question of social justice, as it is an ethical and moral principle of the human condition itself, based on the premise of interdependence that governs human relations. In her book *Learning from my daughter*, the author talks about an ethics of care to meet the "genuine needs" and "legitimate desires" of people with disabilities or chronic diseases. Kittay (2012) articulates not only how individuals like her daughter enrich the lives of those who care for them, but also how caring relationships and the duties that these relationships involve should be.

As we can infer from this discussion, the concept of care discussed here is intertwined with the idea of assistance and support networks, whether in the family or at school. Despite the legal advances in this direction with the Brazilian Inclusion Law (LBI) - Law no. 13.146/2015, we still face numerous challenges, as not all education networks have support professionals. João's mother told us that she stays in the classroom to support the teacher with her son. Thus, the mother, who could have the moment when the child is at school to take care of herself, ends up assuming a responsibility that should be institutional. She told us:

> I get exhausted, I get back from therapy, I have to rush and prepare João's lunch to take him to school, if I had a mediator I could go home, have lunch calmly, do the housework, rest and then pick up my son from school. I am still in school to fight for the public school and for my son to have a mediator. (Clara, João's mother, in an interview, January 18, 2021).

The mediator or inclusion support agent, as has also been called in some education networks, is foreseen in the Brazilian Inclusion Law as a school support professional (Law no. 13.146, 2015).

There are still many doubts about the profile and role of this professional in the classroom. Many networks have hired unskilled professionals or even interns for any child with a disability. However, our research carried out within the scope of the Observatory of Special Education and Educational Inclusion (*Observatório de Educação Especial e Inclusão Educacional* - ObEE) has shown that most children demand only more structured interventions and classroom management actions that can be carried out by teachers, provided they have working conditions for this, such as classes with fewer students, didactic material and other resources necessary for a qualified teaching action. This is not the case for children with multiple disabilities like João and Ana Flor. They demand the permanent support of someone, including to feed themselves and perform personal hygiene tasks. We understand that, for cases like these, the support professional must act collaboratively with the other professionals of the school institution, participate in individualized educational planning and mediate pedagogical interventions in partnership with the teacher (Campos, 2016; Campos & Pletsch, 2018).

In addition to the lack of professional and support, the mother also reported being concerned about her son's absence from school because many therapies are scheduled at the same time. Unfortunately, due to the lack of intersectoral actions, we still experience these situations precisely with children who demand greater educational intervention for their learning and development, a central aspect to appropriate fundamental concepts to improve their autonomy and quality of life, as in the case of alternative communication. In addition, as the bioecological perspective of Bronfenbrenner and others that deal with human development, such as Vygotsky's historical and cultural one, it is in the interaction with the difference that we are constituted, learn and develop, because the human being not only is, but he/she is constituted as a becoming"(Pletsch, 2015, p. 21). For children with severe multiple disabilities, the school has a determining role for them to develop new forms of mental/symbolic functioning, based on school activities that enable the appropriation of concepts, their meanings and senses to structure language and thought, already discussed previously.

In fact, both mothers who participated in this research reported the lack of support they had from the State to guarantee their rights and the appropriate therapeutic treatments for their child. João's mother went to court to guarantee the treatment of physiotherapy and others so important to her son. Ana Flor's mother reported that she will do the same, as she has only one day of physical therapy per week for her daughter, and this is insufficient in view of the demands that the daughter presents and the possibilities to improve her functionality, including with regard to greater independence for feeding herself and use of alternative communication boards for example.

Camélia, Ana Flor's mother, also told us about the difficulties she faces in getting around due to the lack of accessible transportation. According to her, this reality ends up impacting the access to the necessary health treatments for her daughter, as well as family leisure activities. Baixada Fluminense, with almost 4 million inhabitants, has enormous social problems, increased urban violence, lack of basic sanitation and drinking water in several neighborhoods in the 13 municipalities in the region, supply of health equipment, in addition to accessibility problems of all kinds and so many others that impact the social well-being conditions of its population. This reality becomes even more difficult for people with disabilities and their families who demand urban accessibility, transportation and public health services that are insufficient or precarious in the region.

Still on this aspect, the interviewees reported the importance of their participation in the "Juntos" [Together] project, developed at the Fernandes Figueira Institute (IFF) of Fiocruz, under the coordination of Sá et al. (2019). The research and extension project focused on developing actions with mothers on care and early intervention with their children. According to Clara's statement, it was during a class at the project that mothers realized that it would be important

> to bring our voices together, a voice is valuable when it has the weight of several voices together, then we started to study and saw that in other states there is already an association, there is already an NGO that fights for the rights of children with CZVS but here in Rio de Janeiro there is not. That is how we started to mature the Association of families of children with CZVS. (Clara, João's mother, in an interview, January 18, 2021).

As we can see, collaborative projects of this nature are fundamental to increasing the knowledge of these families about their rights and the possibilities of development of their children. Furthermore, this is the social dimension of scientific research, because if Science does not contribute to solving life's problems, there is not much to serve for (Garcia, 2003, p. 23).

Final considerations

The main results of the research presented here bring important data and information for the future stages of the project, but also for the elaboration of actions and educational proposals necessary to guarantee the educational and social rights of children with CZVS and their families. They also present evidence on the need to adapt data collection instruments such as the PEM-CY, considering the social reality and social inequality in countries like Brazil, as well as its application to children and young people with multiple disabilities. During the application, we had to introduce new questions about children's participation in activities at home, assessing whether they needed a lot, little or no support to perform them, due to their multiple disabilities. The results of the PEM-CY show that children demand permanent support to participate in activities at home. In addition, it was also clear that mothers seek, through more elaborate or more intuitive strategies, to constantly improve their child's participation and functionality at home, with the family and at school.

Another aspect that has already been highlighted in different research is the emotional and social impact on the lives of the families of children who were born with CZVS. Families have been largely restructured, with mothers having to stop working to dedicate themselves fully to the care of their child, which has a negative impact on family income and social condition.

Despite legal advances in the field of educational and social rights of people with disabilities in Brazil, the research has shown that families do not feel supported by the State, and they often have to call the Judiciary to obtain essential health care. In the case of João's mother, the lack of adequate support also occurs at school, but she continues to believe in public education and hopes that, soon, her son will have a mediator to support him in school activities.

Finally, the pilot investigation data presented here provide us with important clues about the needs and urgencies of families and children with CZVS who entered in 2019 and 2020 at school. The articulation of the different levels of the bioecological perspective of human development, in dialogue with the premises of functionality and the social model of disability, proved to be useful for the elaboration of programs and intersectoral policies for the integral development of these children, improving the quality of life and their well-being. For this reason, investing in collaborative scientific research with the families and professionals who work with these children is essential, as well as promoting continuing education programs for the professionals involved.

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