THEMATIC SECTION: DISABILITY
STUDIES AND EDUCATION

BPC at School Program and Care Policies for People with Disabilities

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ABSTRACT – BPC at School Program and Care Policies for People with Disabilities. The article addresses education, considering its social purposes, its specific epistemic field, and its possibilities of intervention on reality. The research focused on the BPC at School Program (*Programa BPC na Escola*), which aims to monitor and follow up the access and permanence in school of people with disabilities who receive the BPC benefit. The activities took place in the city of Suzano-SP, mainly involving the reading of 337 questionnaires. It is possible to conclude that, although little put into practice, the BPC at School Program remains an important strategy to ensure the right to education for children and adolescents with disabilities, precisely because of its power to induce intersectoral actions.

Keywords: **Inclusive Education. Special Education. Disability. Social Work. Educational Public Policies.**

RESUMO – Programa BPC na Escola e políticas de cuidado de pessoas com deficiência. O artigo trata da Educação, considerando suas finalidades sociais, seu campo epistêmico específico e suas possibilidades de intervenção sobre a realidade. A pesquisa incidiu sobre o Programa BPC na Escola, que visa acompanhar e monitorar o acesso e a permanência na escola das pessoas com deficiência beneficiárias do BPC. As atividades ocorreram no município de Suzano-SP, envolvendo, principalmente, a leitura de 337 questionários. É possível concluir que, apesar de pouco posto em prática, o Programa BPC na Escola permanece sendo uma importante estratégia para a garantia do direito à educação por parte de crianças e adolescentes com deficiência, justamente por sua potência de indução de ações intersetoriais.

Palavras-chave: **Educação Inclusiva. Educação Especial. Deficiência. Assistência Social. Políticas Públicas Educacionais.**

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A research on intersectoriality and interdependence based on an education framework

The general theme chosen for research[1] is the right to education by people with disabilities, more specifically those of school age who live in a situation of extreme poverty, that is, exposed to the intensification of vulnerabilities, since they live the effects of the system of oppression that constitutes disability (ONU, 2006) and do not have the basic minimums rights for their survival guaranteed (FGV Social, 2018).

> The social model of disability understands that social relations are configured as a system of oppression that mischaracterizes, diminishes, and, consequently, lowers the dignity of people with disabilities, as it not only interposes barriers to the dignified exercise of their lives, but also refuses their bodies, their ways of perceiving, thinking, feeling, and communicating (CAMPBELL, 2009). Thus, disability consists of a situation experienced by people who live sensory, physical, mental, and/or intellectual impediments who are insistently denied in their condition as humans. It is clear how it is not possible to conceive disability as a characteristic of a subject, but as a social process that frontally degrades the recognition of human dignity. In this sense, inclusive education, as an ethical principle (PLAISANCE, 2010), frames the public education policy and, consequently, educational systems, as state initiatives to radically confront the production of disability, as well as to restore the legitimacy of all subjects, recognizing and exalting human variability, here elevated to a desirable value, since it allows to criticize and renegotiate patterns of sociability (Angelucci: Costa, 2023, p. 178-9).

The research addressed the ongoing public policy, which means that the school education of people with disabilities was not approached theoretically or generically, but apprehended from an organized and intentional state action, with foundations, execution and monitoring parameters. The place from which we study the theme is education, considering its social purposes, its specific epistemic field, and its possibilities of intervention on reality.

Considering that the guarantee of rights is not done in isolation (Calderón-Almendros; Echeita-Sarrionandia, 2022), we consider it strategic to monitor the implementation of an intersectoral program from its origin (derived from Interministerial Normative Ordinance 18/2007 (Brasil, 2007b), involving Social Work, Human Rights, Education, and Health), which requires the formation of an interdepartmental management group for its implementation within the municipalities and states.

The BPC at School Program was created in 2007, but we worked with questionnaires – which make up the intervention and registration strategies of the program – applied in 2014 and 2018, because the previous material (applied in 2009), in addition to presenting some inconsistencies, referred to people who had practically not experienced inclusive education, which became a state policy in 2008 (Brasil, 2008). Therefore, the information recorded would not concern the current policy. As our study is not intended to compare inclusive and other systems, we chose to work only with the records from 2014 on.

It should be noted that the research material allows readings on different fields of the rights of people with disabilities (leisure, work, urban mobility, health, justice); however, in this research, we focused on the rights to social protection and education, whose policies of Social Work and Education seek to put into effect.

After the coup experienced in Brazil in 2016 (Souza, 2017), there have been numerous initiatives to dismantle public policies, especially those that face inequalities in the country. Thus, Social Work policies, as well as the ordinances and agencies that regulate the rights of people with disabilities, have suffered daily attacks. In this article, we chose not to enumerate or even analyze the effects of these attempts. This is an ethical-political option that does not recognize the legitimacy of attempts to deconstruct the rule of law that defends the social achievements of our population by democratic mechanisms. Although we recognize that attempts to implement fascist ideas have an impact on the daily work in institutions, this study does not intend to open space for debate on the feasibility or attempts to implement such an idea. Like all scientific work, we stand in defense of any debate, as long as it is based on ethics and the defense of human rights. Rights previously achieved will not be questioned. We will not allow fascist discourses.

Research problem

Special education (in an inclusive perspective), as a modality of school education (Brasil, 1996), is an inalienable right of every subject with disabilities, guaranteeing access and permanence in a quality school. Moreover, from the promulgation of LDBEN/96 and the National Policy of Special Education in the perspective of Inclusive Education of 2008 (Brasil, 2008), these[2] students have the right to Specialized Educational Care (Brasil, 2009a; Brasil, 2011a). The service involves, among others, the possibility of attending the multifunctional resources room in second shift, that is, in no case it replaces the enrollment in common class of the regular education network.

At the end of the 20th century, the Social Work Policy, regulated by the Organic Law of Social Work (Loas) (Brasil, 1993), started to act in the field of rights, universalization of access, and state responsibility, composing the Brazilian social welfare system. In this context of recognition of the inequities of our country and commitment to tackling poverty:

> Art. 20. The continuous provision benefit is the guarantee of a minimum monthly wage to the person with disability and to the elderly aged 65 (sixty-five) years or more who prove that they do not have the means to provide their own maintenance or to have it provided by their family.

In a survey of the BPC at School Program throughout 2009 in the city of São Paulo-SP (São Paulo, 2010), the general results indicated that, out of the 730 interviewees, 144 had never attended school and 107 had already attended, but, at that time, were not enrolled. Regarding possible reasons alleged by the families for non-attendance, three main reasons were listed: a) families discredit the possibility of the child/adolescent being able to learn; b) school did not create conditions for permanence; c) school refused enrollment. Among those who had already attended school, 39.6% had only completed early childhood education and 17% had completed the first grade of Elementary School. Considering this context, we hypothesized that the BPC at School Program could be configured as a significant support in the process of identifying obstacles to the implementation of the right to school education. It would also be possible that, because it is an intersectoral initiative, it would encounter many challenges for its achievement, although it carries a strong potential for articulating state actions. In this sense, we ask: what the BPC at School Program can teach us about the production of care policies for people with disabilities that result in advances to ensure the right to education of this segment of the population?

The thesis defended is that a school education of people with disabilities really committed to the ethics of inclusion (Plaisance, 2010) depends on the organization of a care policy for this population segment, which should be organized as a public policy, based on the National Social Work Policy (PNAS, 2004). When we allude to care here, we are referring to the ethics of care and the policies of care, as theorized by Feminist Disability Studies, more specifically, by Joan Tronto (2007), Fiona Kumari Campbell (2009), and Eva Kittay (2011), which we will discuss later. For now, we emphasize that this notion of care implies radical criticism of capitalism and its form of privilege production; recognition of the interconnection of systems of oppression, requiring the use of intersectionality (Collins; Bilge, 2021) as a tool for analyzing concrete living conditions; legitimization of interdependence as constitutive of experience and desirable value of/in humanity; and promotion of social justice.

Feminist Disability Studies have significant importance for epistemological education, since, starting from the premise of interdependence and the recognition of collective responsibility for care, they indicate ways to make inclusive education effective (Lopes; Ferreira; Gesser, 2022): it is about recognizing vulnerability as inherent in the human experience and producing collaborative forms of care for all among all, which necessarily implies two important confrontations, namely, the ideology of opposition between caring and educating; the domination of neoliberal logic that tries to impose itself on both educational policy and pedagogical ideology.

BPC at School Program

The Continuous Provision Benefit (BPC—*Benefício de Prestação Continuada*) is characterized as a welfare benefit, operationalized by the National Institute of Social Security (INSS) (Brasil, 2007a), that is, one does not need to meet insured contribution requirements to obtain it, because according to Article 1 of the Loas (Brasil, 1993), Social Work is a non-contributory policy and a citizen's right and duty of the state. Its main objective is the protection of people in situations of social vulnerability, that is, the elderly and people with disabilities who are unable to provide their livelihood or have it provided by their family. For this, one of the requirements for receiving the benefit is that the per capita income of the family must be less than 1/4 of the minimum wage.

Regarding people with disabilities, Law 13.146/2015 amended the Loas, providing the following wording for the definition of a person with disabilities:

> Art. 20 § 2 For the purpose of granting the continuous provision benefit, a person with a disability is considered to be one who has a long-term impairment of physical, mental, intellectual, or sensory nature, which, in interaction with one or more barriers, can obstruct their full and effective participation in society on equal conditions with other people (Brasil, 1993, emphasis added).

The Continuous Provision Benefit (BPC)

The program for monitoring the access and permanence in school of people with disabilities who receive the continuous provision benefit from Social Work, known as the BPC at School Program, is characterized by its intersectoriality, aiming to expand the social protection of children and adolescents with disabilities receiving the BPC, guaranteeing them access and permanence in school. For this, it aims to identify barriers to access and permanence in school; as well as monitor, by the social work services of the municipality, the beneficiaries and their families (Brasil, 2016)

To implement the BPC at School Program, the interested municipalities must sign a Term of Adherence and create a Local Management Group (GGL), which will work on the articulation of these public policies aimed at improving the quality of life of people with disabilities. The axes of action of the BPC at School Program are:

1. To identify BPC beneficiaries, from 0 to 18 years old, who are and who are not attending school;
2. To identify the main barriers to access and permanence in school for children and adolescents with disabilities beneficiaries of the BPC;
3. To conduct studies and develop joint and cooperative strategies to overcome these barriers and;

4. To carry out systematic monitoring of the actions implemented by the Program (Brasil, 2007a).

The barriers that promote school exclusion are central indicators in the BPC at School Program. E, unlike other social benefits, BPC has no conditions. Therefore, in the case of the population assisted by the BPC at School Program, it is not necessary to attend school to receive it. The follow-up and monitoring of the beneficiaries of BPC should be organized by the articulation between different administrative spheres and the policies of education, health, social work, and human rights. The municipality that adheres to the Program, by creating the Local Management Council (CGL), which is coordinated by the Social Work Ministry, begins to systematize a set of information and records about people with disabilities and public policies aimed at them. The basis for the planning of the actions is the analysis of a questionnaire to be applied periodically to each BPC beneficiary who has a disability and is between 0 and 18 years old. People over the age of 18 can be included, but they are not part of the priority of the program. The analysis of this material, together with the discussion of existing public policies, the budget, the municipal plans for each agenda, and the dialogue with civil society, mainly by the social control agencies, constitute the basis of all planning.

Using the expression “apply the questionnaire” seems to us insufficient to make explicit the power of production of experiences that it carries. As Saraiva (2019) discusses in their postdoctoral report, it is not merely a matter of carrying out 119 questions, but of establishing relationships so that the living conditions of the person with disabilities, their participation in social life, can be the subject of reflection both by professionals and by the person with disabilities themselves and their families. Likewise, people involved in daily care are also called to share their living conditions and their perspectives on barriers. The emphasis in the guiding documents for the home visit is not instrumental, but is configured as an active search strategy, considering that both people with disabilities and those involved in their daily care experience restrictions on social participation (Human..., 2018).

Methodological choices

Often, the relationship of researchers with the field, especially that involving institutions and public agents, are narrated as epic stories: the list of contact attempts, the long waits for meetings, the frustrated meetings, the communication difficulties. Often, the interpretation generated is of obstructions to the research. We would like to propose another way of relationship and, therefore, of reading the events of field research.

When we contact public agents to propose conducting research, we are asking for the creation of spaces and times in institutional life. We ask for time for conversation and reflection, we ask for organization of meeting places and creation of work spaces to accommodate us. Our presence creates new events not only for people with whom we relate directly in public institutions: sometimes the coffee dishes change, the arrangements in the shared work rooms change, the attention and mood of those who are nearby change. We occupy spaces with our bodies and proposals, we dispute agenda with the emergencies of everyday life, with the time of rest and ordinary tasks. Given this, how to hope that there are no situations of canceling, going over, and emptying meetings?

Furthermore, our research period was marked by two times: from 2017 to 2019, with face-to-face meetings; from 2020 to 2021, with remote meetings, due to the COVID-19 pandemic.

Research material

The research consisted of which materials? We used four sets of sources: regulations on Social Work, BPC, and BPC at School Program; scientific publications that focused on the BPC at School Program; individual and collective conversations with the professionals of the Departments of Social Work and Development, Education, and Health of the municipality of Suzano; questionnaires that make up the BPC at School Program and that are periodically applied by the professionals of the municipality to each beneficiary or person responsible for them. These are standardized questionnaires, sent by the federal government, individualized, with the recommendation to be applied during as many home visits as necessary to complete them. The then Ministry of Social Development and Fight Against Hunger (MDS), responsible for proposing and conducting the BPC at School Program during the administrations of Luiz Inácio Lula da Silva and Dilma Rousseff, produced a significant set of training materials for the federated entities to use with their teams: they consist of compilated regulations, instruction guides, questionnaire application manuals, among others[3].

The questionnaire[4] of the BPC at School Program must be applied individually and contains 119 questions thus grouped:

1 to 14 - identification of the beneficiary

15 to 24 - address of the beneficiary

25 to 30 - identification of the interviewee

31 to 39 - address of the interviewee

40 - type of disability

41 to 81 - school

41 - access or not to school

42 to 63 - whether they claim to attend

64 to 74 - whether they claim to have already attended, but do not currently attend

75 to 81 - whether they claim to have never attended

82 to 84 - work (only for situations where the beneficiary is 14 years or older)

85 to 87 - products and medicines used by the beneficiary
88 to 90 - products and equipment used by the beneficiary
91 to 93 - orthoses and mobility aids used by the beneficiary
94 to 99 - care and relationships
100 to 106 - health
100 to 102 - health care
103 to 106 - rehabilitation
107 to 109 - service network
110 - defense of rights
111 to 113 - access and free public transport
114 to 118 - housing and environment
119 - justification for non-completion (when applicable)

Within the scope of this research, we will work with the set of questions related to the characterization of beneficiaries (1 to 14), type of disability (40), and care and relationships (94 to 99).

Suzano is part of the Alto Tietê region, in the state of São Paulo. It is a large municipality (population of more than 300 thousand inhabitants), with high HDI (0.765), schooling rate from 6 to 14 years of 96.7%, and 3,433 people with disabilities, according to information from the Brazilian Institute of Geography and Statistics (IBGE) in 2010. According to the Municipal Education Plan 2015/2025 of the municipality of Suzano, there were, in 2015: 23,289 students in Early Childhood Education; 22,468 in the initial years of Middle School; and 11,503 in the final years. The municipality does not offer High School programs. Regarding the target audience of special education, the following record appears in the 2015/2025 Plan: 227 students enrolled and 78 case studies being conducted at that time.

What the studies already carried out indicate

Here we briefly discuss the only study directly related to the theme: the research commissioned by the Ministry of Social Development and Fight Against Hunger, which, because it was not available, had to be accessed via the Access to Information Law (LAI), which was quickly granted. The knowledge about this study is due to the proximity to Ana Rita de Paula, a researcher and activist, woman with disability, responsible for the elaboration and evaluation of many public policies aimed at people with disabilities in Health and Social Work. Paula's (2012) study aimed to analyze the questionnaire of the BPC program throughout the Brazilian territory, measuring the degree of access of people with disabilities to the network of basic services, such as health, social work, work, and education. It also characterized the population in terms of needs and demands, comparing differences between Brazilian regions. In her work, relationships between disability, poverty, lack of health care, and violence are established, explaining the intensification of the vulnerability of the studied population. The information systematized by the author indicated a rate of 17.9% of female students who never attended school.

In the search for similar studies, we found the Executive Summary commissioned by the Ministry of Social Development and Fight Against Hunger, a study conducted between 2014 and 2016, which sought to offer subsidies to improve the implementation of the BPC at School Program. Its suggestions are in line with Paula's (2016) analyses that emphasize the need for coordinated intersectoral action, with planning based on territorial analyses. The questionnaire allows mapping not only the social demands and weaknesses of the state, but also allows a territorial reading of the events, enhancing the production of strategies from the different public facilities that make up the social protection network. Thus, it is not a question of carrying out general readings on the schooling of children and adolescents with disabilities, but of inscribing the strategies in the networks already constituted, strengthening and expanding them. Such analyses find dialogue with the discussions made by Patricia Hill Collins and Sirma Bilge (2021) about intersectionality as an analysis tool rather than as a concept. The two authors, by dedicating themselves in depth to the discussion of the ways in which intersectionality can compose readings of complex events involved in situations of oppression, indicate the importance of considering the usual categories such as gender, age, race, ethnicity, class, regionality, religion, capacity, etc., as well as to pay attention to other categories such as territory and labor organization, for example.

We refer the two findings of the literature review to discussions on intersectionality because, although they do not mention this analysis tool, they converge in the emphatic recommendation that the readings – and consequently the planning of actions – that derive from the questionnaire should serve from the situations and concrete possibilities of intervention in reality. It is not a question of creating generalization with a universalizing claim, even if there is study and guidance at the national level. Either the numbers gain geopolitical location or they will not serve for political construction. As an example, we can cite the reality of the municipality studied: when we find five visually impaired people who receive the BPC, it is not a matter of saying that this public does not need to be prioritized. Nor is it about buying assistive technology, Braille machines, canes, and school equipment suitable for people with visual impairments. Rather, it is a question of referring to the territories inhabited by them the accessibility demands indicated by them, materially, regarding the barriers experienced in daily life. It is interesting to know their age group, their relationship with the neighborhood and its public facilities. The demand can be for a place in a daycare center, for a guide, for accessible parks. In other words, the discussions focus on a very serious issue for the principle of economicity in public management: it is not about buying accessibility kits, as schools and other public equipment often do, but about reading the unique demands and to subsidize the territorial strategic planning politically, financially, and technically. In line with feminist disability studies, it is not a question of presenting abstract answers to accessibility demands, but of knowing everyday reality and, from it, building, in a participatory way, historically and politically determined solutions.

In the context of discussions on reconfiguration of the meanings of public management, Paula (2016) points out a crucial element: the overload of functions by Social Work concerning the BPC at School Program, even though other areas are also involved. The researcher points out that, in Health, the main aspect concerns the responsibility of the Brazilian Unified Health System (SUS) for the monitoring, treatment, and rehabilitation of beneficiaries. 81% of the questionnaires analyzed by Paula (2016) reported having health follow-up, with 75.7% stating that they used the health center and 47.7% indicating that they were monitored by community health agents. In other words, most of the beneficiaries attended primary health care facilities, which could boost strategies to approach the beneficiaries and their families, since many still relate to CRAS as a registry office, which only performs registrations and updates and verifies information.

Producing meetings and weaving networks of analysis of events

The research and the researchers were hosted at the Department for Social Work and Development (SMADS) of the municipality of Suzano, which occupies one of the floors of the building holding different departments, next to the City Hall. Meetings with the management team of the Department took place there. On the other hand, the meetings with the management team and teams from the Reference Centers for Social Work (CRAS) took place in a training school, also in the central region of the city.

In these five years, there were four secretaries (all men), requiring the presentation of the research and request for its continuity each of these times. Such changes in management also implied changes in commissioned positions, the BPC management board, as well as changes in work dynamics, including those related to the monitoring of BPC beneficiaries. Also during this period, a new CRAS was created (totaling five), as well as the Municipal Council for People with Disabilities, with the participation of entities from and for people with disabilities and government representatives.

After the first presentation of the research to the Secretary and the Social Work Surveillance team, meetings were scheduled with representatives of the departments of Health and Education, who would be designated by their respective areas, so that we could think collectively about how the BPC at School Program was taking place in the municipality. The municipality does not have a Human Rights Department, which is why this area will not be mentioned throughout the text.

The meeting with colleagues from the three Departments had the intention to present the Program, since the representatives of Health and Education did not know about it. We then talked about what each Department was doing in the area of rights of people with disabilities. In Health, in addition to mental health services, there was the distribution of orthoses and prostheses. There is no Specialized Rehabilitation Center (CER) in the city, equipment that, according to the National Health Policy for People with Disabilities (Brasil, 2010), must accommodate the health demands of this sector of the population. Thus, people with disabilities and their families seek care in the municipalities of Mogi das Cruzes and São Paulo, which implies investment of time and money in health care. Education offers Specialized Educational Care (ESA) in the form of a multifunctional resource room. None of the Departments had, at that time, any strategy for intersectoral dialogue on the subject, just as there was no plan to actively search for people with disabilities without assistance in basic facilities (schools, Basic Health Unit (UBS), and CRAS). We all left the meeting with the certainty that there was no policy of attention to people with disabilities in the municipality and that it was possible to start small initiatives, such as the dissemination of the BPC among users with disabilities in each service and the survey, also among users, of those who already received the benefit.

About a year and a half later, we attended another meeting with the teams of the three Departments. The referrals had not been continued. Our hypothesis, which will be discussed later, is that the BPC Program is very deeply rooted in Social Work, not constituting, in fact, an intersectoral program. The imbalance of forces between the areas and the decision on budgetary allocation for this Program force the search for an area responsible for the theme and, given the characteristics of the Program, as we will present in more detail, only one answer has been possible.

In the first two years, some meetings were held with SMADS professionals who had been responsible for monitoring the BPC. With that, we understood what had already been done, had access to the documents, and discussed how to proceed from there. We created a route with two axes: the visit to each Social Work equipment (there were five CRAS and one Specialized Social Work Reference Center (Creas)), in which we would get to know the professionals, the conditions and work routines and we could talk to each management to get to know the work with users with disabilities; specific training meetings for Social Work professionals, to detail the BPC Program and discuss the application of the questionnaire that is part of it, and extensive meetings with professionals from the three Departments, which had the purpose of creating possibilities for work articulation. And, from time to time, we held a meeting with the Secretary who had just assumed the SMADS to present the research, inform what had already happened, and renegotiate the continuity of the work. Notably, the research or the discussion of its results was restricted by any means.

Before the pandemic, we were also able to hold a specific meeting for Social Work and one for the three Departments to present the partial results of the research. No results were disclosed orally or verbatim without first being discussed with the SMADS professionals. With this, we hoped to engage in dialogue the possible analyses and create interpretative frameworks rather than disputing the correct reading of events or quantitative information.

The pandemic was recognized only in March 2020, with the respective policy of social isolation. At this time, we were compiling some of the latest information and elaborating the results of the research. We then held a virtual meeting only with SMADS managers to plan the final discussion. This is how we established a virtual meeting with the CRAS professionals and, from it, a virtual meeting also open to the Municipal Council of People with Disabilities and Health and Education professionals. In total, there were 20 meetings, three of them virtual.

According to the SMADS management team, in June 2017, there were 478 people with disabilities between 5 and 17 years old, out of a total of 2,623 people with disabilities who received the BPC in the municipality at the time. The last application of the questionnaire had occurred in 2014, and it had not been digitized and systematized. Thus, we proposed to create a spreadsheet with all the information, to be shared with the management team. Thus, an Excel spreadsheet was created, in which each column corresponded to one of the 119 questions and each row corresponded to the answers marked on the paper questionnaires used by the professionals at the time. From this first spreadsheet, others were created: questionnaires answered, questionnaire not answered, questionnaires answered and not answered by CRAS.

In 2018, still during the research, the State Department requested all beneficiaries who registered after 2014 to be called to respond to the questionnaire. Thus, we duplicated the spreadsheets, with information referring to 2014 and 2018 separately. SMADS received the spreadsheet in full. For the purposes of this research, we removed all columns that could generate identification of the beneficiaries, their families, and schools they attend. Therefore, each person received a number, which ensured that we could identify all the answers of the same beneficiary, without, however, breaking the anonymity. The names of CRAS remained the real ones, so that it is possible to identify the set of beneficiaries that inhabits that territory, as well as their demands.

Table 1 – Completed and blank questionnaires by year, by CRAS – 2014 and 2018

	CRAS	A	B	C	D	E	NOT IDENTIFIED	TOTAL
2014	NOT ANSWERED	23	25	12	21	1	26	108
	COMPLETED	56	32	55	60	52	0	255
	TOTAL	79	57	67	81	53	26	363
2018	NOT ANSWERED	3	3	2	2	1	8	19
	COMPLETED	14	11	25	18	14	3	85
	TOTAL	17	14	27	20	15	11	104
TOTAL	NOT ANSWERED	26	28	14	23	2	34	127
	COMPLETED	70	43	80	78	66	3	340
	TOTAL	96	71	94	101	68	37	467

Source: Prepared by the author based on the Program questionnaire.

In 2014, 363 questionnaires were applied, of which 255 were completed and 108 were not. Among those not answered, 26 could not even be identified in relation to the reference CRAS, hindering further attempts to contact the beneficiaries.

In 2018, 104 questionnaires were applied, of which 85 were answered and 19 were not. Among those not answered, 8 did not have the reference CRAS identified, and among those answered, 3 were quite incomplete, making it impossible to identify the CRAS and consistently record other information. After discarding the blank questionnaires and the 3 incomplete ones, we worked on 337 documents.

The blank questionnaires were mostly due to changes of address not reported to CRAS. In two cases, the beneficiary died.

As a first and fundamental result we have that, of the 337 respondents, only 26 were people with disabilities themselves. In the others, no mention was made of the presence of the beneficiary at the time of the so-called application.

Characterization of beneficiaries

Both in 2014 and 2018, we noticed the predominance of beneficiaries in the range of 3/4 to 17/18 years. The lower number of people over the age of 18 is understandable given the scope of the program. On the other hand, the low number of people under 3 years of age can be explained both by the very characteristic of the diagnostic process, which is not carried out immediately.

In both periods, the number of persons of the male sex[5] is higher than females, contradicting the general population information. If in 2014 there was a rate of almost 30% more boys, then in 2018 this difference drops to about 20%.

In terms of race/color, there are significant differences concerning the two periods of application. If in 2014 black and brown people made up the number of 100 respondents, white people made up 139.

In 2018, black and brown people add up to 40, the same number of white people. In both periods the presence of indigenous people is minimal.

As the last aspect of the general characterization of the beneficiaries, we will present the item type of disability, as expressed in the questionnaire.

If, in 2014, we had a prevalence of people with intellectual disabilities, followed by people with multiple disabilities and physical disabilities, in 2018, the presence of people with intellectual disabilities and multiple disabilities equated, with a significant decrease in the occurrences of physical disabilities and an increase in the occurrences of global developmental disorders and chronic diseases.

In both periods, the presence of people with visual or hearing impairment/deafness is very small. Although its percentage of occurrence in the population is, in fact, lower than other impairments, we are struck by such low numbers: 9 with visual impairment and 10 with hearing impairment/deafness.

There is no field in the form to explain which are the chronic diseases, so there is no way to know what concrete conditions make up this category.

Regarding situations of multiple disability, it is worth noting the constancy of reports of intellectual disability combined with global developmental disorders or chronic diseases. Given the discussions in the field of intellectual disability (GOULD, 1991), we hypothesized that the communication barriers experienced by autistic people and people with physical disabilities would result in diagnostic processes in which a cognitive impairment is also assumed.

In summary, we could say that, in the municipality of Suzano, we have a predominance of boys, white and black in almost equal proportion, with intellectual or multiple disabilities who receive the benefit. However, in doing so we are head-on hurting both the recommendations of the guiding documents on the BPC at School Program and the discussions on intersectionality. The quantification of each characteristic cannot result in the production of an abstract, deterritorialized subject. In possession of the detailed tables, which were made available to the teams of professionals, it would be up to the Local Management Committee (CGL) to organize discussions within the territories, to discuss who are the people in that context: being a wheelchair user in a neighborhood full of slopes and with unpaved streets demands different interventions than being a wheelchair user in downtown neighborhoods with paved streets and a lot of traffic. As the first generation of the social model of disability (UPIAS, 1975) taught us, impairment and disability are not equivalent. People with the same disability can experience very different barriers and need different supports.

It happens that the second generation of the social model, marked by Feminist Disability Studies, brought other elements to think about the guarantee of rights: the assumption of interdependence as a human condition in the world, implying the discussion about the ethics of care, which makes the reading of reality more complex.

Caregivers and network production

The second generation of the social model of disability brings important questions to the field of Disability Studies, especially those concerning the expectation of independence, an idea so dear to liberal capitalism (TRONTO, 2007). In fact, the author explains to us a torsion operated by capitalism: it is not a question of desiring independence, but of establishing certain privileged relations of dependence. What does that mean? A man who holds an executive position and receives a high salary can boast that he does not know how to cook, take care of the house, or change diapers. Because in the care economy, this type of dependence, that of normofunctional people who, with their money, can pay for care, making it a subordinate service, is well received. Tronto (2007) shows how the conversion of care needs into consumer goods by those who can pay for services provided and, therefore, reverted to the logic of capital, when becoming an expression of privilege, also become elements of status. From this operation, we have two developments: the rupture of care as a social practice that recognizes interdependence and puts reciprocal concern at the center of the ethics of coexistence; the expropriation of this value transformed into a dead thing, instrumental work to be negotiated according to the laws of the market.

Thus, the authors of the second generation, who have been working on this topic for decades, help us to understand more deeply the socioeconomic and political-affective implications of the production of women's place in care relationships (Kittay, 2011). How do you define care?

> […] an activity of the species itself that includes everything we can do to maintain, continue, and repair our “world” so that we can live in it in the best possible way. This world includes our bodies, ourselves, and our environment, and everything in which we seek to intervene in a complex and self-sustaining way (Fisher; Tronto, 1990, p. 287).

Under the sign of the loss of care as a value of and in relationships, we have both erased the work dimension that constitutes our tasks with the house, the elderly, children, people with disabilities and are considered inferior when we professionalize these cares — given the devaluation of professions considered linked to care, such as domestic workers, nurses, teachers of children. And how does this appear in the questionnaires? By the isolation of the person with disabilities and their mother, in a double process of precariousness of life, since social interactions are greatly weakened.

Returning to the readings on the questionnaire of the BPC at School Program: 304 of the 337 people are indicated as needing care for activities of daily living. Another five are indicated as needing support without, however, being able to count on it. Only 27 people are referred as not needing care. It remains to be seen who offers such care.

In 236 situations, the mother is referred to as the sole caregiver, in another 22 the care is carried out by the mother and another person in the family. Meanwhile, the father is referred to only seven times as the sole caregiver. Throughout the training sessions with the CRAS teams, many stories were related with the character of neglect by the mother: children with disabilities were locked at home so that the mother could go out alone; young women with disabilities were prevented from going to school at night, because no one was willing to accompany them on the way to and from school. Such situations gave rise to the debate on two productions of the state: the disability of the person and family neglect. The production of disability is better known in debates related to the social model, since the absence of policies, the pauperization of people who experience disabilities, the constant violation of their rights, when configured as barriers that prevent both the recognition of the legitimacy of the subjects and the exercise of their dignity, produce disability (ONU, 2006). The production of neglect, on the other hand, was not so noticeable at first, since the moralization of the practices of family members, especially mothers, with children and adolescents with disabilities seemed to prevent ethical reflection on who is responsible for caring. As Saraiva (2016, p. 174) teaches us:

> Public responsibilities are not exactly privatized; certain responsibilities become familiar, becoming “natural” functions of the family. They are constructed as its assignments. One tries to build a family convinced of this, a family that also desires such assignments.

Thus, the naturalization of the family as a unit obliged to the continuous provision of care, as well as the assumption that any practice that questions this corollary is an act of lack of love, had to be exposed to a long ethical debate. Little by little, we were able to enumerate state strategies that share care, recognizing their co-responsibility in guaranteeing support to people with disabilities. We were also able to discuss the daily practices of public facilities that, instead of collectivizing care, end up overloading the caregivers. Some examples: recognizing the low attendance of people with disabilities to CRAS activities, “caregiver care circles” were proposed. Undoubtedly, overload and isolation were recognized, as well as the need for a space in which they could be subjects to themselves and not to others. It happens that, by not creating possibilities for people with disabilities to be cared for by someone (from the institution) during this period, the participants - especially mothers - either could not be present or brought their children to the activity. Another practice discussed was related to the constant call of the caregiver for registration activities and other initiatives related to the guarantee of benefits for people with disabilities. We recall that, of the 337 questionnaires, only 26 were answered by the beneficiaries themselves, even though more than 50% of them are adolescents or young people. Thus, ableism (Campbell, 2009), a process in which we assume people's (dis)abilities and begin to establish relationships with them based on these assumptions, reducing their expressions of life, their legitimate and autonomous participation, is also in the dynamics of institutional relationships. When we face difficulties in contact with people with disabilities, we follow the obvious path: that of demanding that the caregiver act as a prosthesis of the body that does not move, of the identified speech, of the reasoning that we do not reach, of the communication that we do not produce. We position, then, not only the person with disability as a defective object, but also the caregiver — in general, the mother—as an object-part, in charge of making the crippled body disappear, by assuming for herself the functions that were intended to be present.

In this sense, the analysis of access barriers, the adequacy or insufficiency of specialized educational care or teacher training in and for inclusive education, all important elements and widely explored by the specialized literature (Prieto et al., 2017; Garcia, 2021), need to refer to the principle of participation of people with disabilities and, consequently, must provide different support systems. Direct participation implies public policies of care, that is, defamiliarization of care. As discussed during one of our last training activities: caring for the caregiver, at the limit, is to exempt her from the obligation of uninterrupted, solitary, and precarious care. Thus, a public care policy needs to recognize interdependence; legitimize forms of life that imply continuous, varied, and complex support; and provide not only resources, prostheses, orthoses, medicine, food, and supplies. Undoubtedly, these are important and need to be expanded, as Ana Rita de Paula (2012) already indicated, but also light technologies, as already taught by Emerson Mehry (2002), supported by living networks of professionals who take up the ethical dimension of care not as a commodity, but as a fundamental value of intersubjective relationships.

Final remarks

It is worth reflecting on how we have dealt with the inheritance we have received in Inclusive Education. One way could be to pursue the traces of biomedical thinking in our research, asking ourselves how we deal with people with disabilities (often presented only by their impairments; not being constituted also by their places of class, gender, sexual orientation, ethnicity/race). It would also be important to systematize what accessibility resources we have created for the participants of our research or even for the dissemination of its results. In other studies (Freitas, 2019; Freitas; Angelucci, 2019), it is explicit that people with disabilities who do not predominantly use oral communication are passed over in research, under the justification of… not communicating orally. In other words, we defend the universalization of the right to education and accessibility of/in the curriculum to all people, but we do not care to create means that guarantee dialogue with people who use non-oral communication modalities to produce knowledge in special education.

What clues do we already have on how to get education to people with disabilities? We can broaden our connections with Sociology of Childhood (GOBBI, 2014) as a field of knowledge that has sought to experiment with ways of being with children in different contexts and, mainly, using multiple languages. We can rely on the invitation to multiple languages, not only regarding children, but concerning all people with disabilities, expanding our joint repertoire of research techniques. Regarding people with intellectual disabilities, such expansion has meant, as pointed out by studies carried out by Santos (2021) and Santos and Angelucci (2022), rethinking temporality and being willing to build thought paths with the use of material and human supports — including supported decision-making —, considering cognitive schemes that are not as linear as our pre-structured research instruments, whether questionnaires or interviews.

Finally, the authors of the Disability Studies (Garland-Thomson, 2002; Campbell, 2009) would recommend that we crip education: to produce expansion in the ways of communicating, recording, participating, occupying spaces. And exercising such an ethical mandate, for those who have learned (and taught) that it is ugly, demerit, and disabling, is not a task to be carried out in isolation and instantly. Either we put ourselves in more company with people with disabilities and we are willing to support ourselves as a collective of researchers – diverse and divergent – that sustains in common an ethical-political commitment to radical combat against fascism that has been breaking doors, windows, bodies, and institutions; or we will be able to do little.

We highlight that, despite little put into practice, as the literature points out, the BPC at School Program remains an important strategy for ensuring the right to education to children and adolescents with disabilities, precisely because of its power to induce intersectoral actions, which can bring more effective responses to the deep social, cultural, and economic barriers that impair the exercise of rights and, thus, end up producing situations of disability, in the sense affirmed by the Convention on the rights of persons with disabilities (Brasil, 2009b). It is in this sense that the weaving of the protection network is so important, because what returns a child or adolescent who has had their rights violated to the world is the possibility of circulating to find another world, to produce other belongings. And this is done with state policies, community participation, and constant social tension, especially from the academia[6].

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Notes

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[2] The text is written in the feminine plural as an invitation to reflection, to displacement. We seek to produce a communication in which women are not supposed or implied, but directly identified, summoned. A communication in which men move, ally themselves with women, and strengthen the production of a science from feminism.

[3] Some materials can be found in Brasil (2011b).

[4] See the manual at: https://www.mds.gov.br/webarquivos/publicacao/assistencia_social/Cadernos/Aplicacao_Questionario_Identificacao_Barreiras_Programa_BPC_Escola.pdf.

[5] We used the term sex, in accordance with the questionnaire, because we do not know – and the questionnaire does not allow this distinction – whether the information given was related to sex or gender.

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